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ABSTRACT

In February 2001, President George W. Bush announced his New Freedom Initiative to promote increased access to educational and employment opportunities for people with disabilities. In his charge to the Commission, the President directed its members to study the problems and gaps in the mental health system and make concrete recommendations for immediate improvements that the Federal government, State governments, local agencies, as well as public and private health care providers, can implement. The Commission's findings confirm that there are unmet needs and that many barriers impede care for people with mental illnesses. After its yearlong study, the Commission concludes that traditional reform measures are not enough to meet the expectations of consumers and families. The Commission identified the following six goals as the foundation for transforming mental health care in America: Americans should understand that mental health is essential to overall health; mental health care should be consumer and family driven; disparities in mental health services should be eliminated early; mental health screening, assessment, and referral to services should be common practice; excellent mental health care should be delivered and research should be accelerated; and technology should be used to access mental health care and information. This report discusses each goal in depth, showcasing model programs to illustrate the goal in practice and providing specific recommendations needed to transform the mental health system in America. (Contains 183 references.) (GCP)

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THE PRESIDENT'S NEW FREEDOM
COMMISSION ON MENTAL HEALTH

Achieving the Promise:

TRANSFORMING MENTAL HEALTH CARE IN AMERICA

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FINAL REPORT

JULY 2003

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The President's New Freedom
Commission On Mental Health

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July 22, 2003

Dear Mr. President:

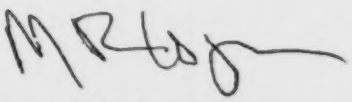
On April 29, 2002, you announced the creation of the New Freedom Commission on Mental Health, and declared, "Our country must make a commitment. Americans with mental illness deserve our understanding and they deserve excellent care." You charged the Commission to study the mental health service delivery system, and to make recommendations that would enable adults with serious mental illnesses and children with serious emotional disturbance to live, work, learn, and participate fully in their communities. We have completed the task. Today, we submit our final report, *Achieving the Promise: Transforming Mental Health Care in America.*

After a year of study, and after reviewing research and testimony, the Commission finds that recovery from mental illness is now a real possibility. The promise of the New Freedom Initiative—a life in the community for everyone—can be realized. Yet, for too many Americans with mental illnesses, the mental health services and supports they need remain fragmented, disconnected and often inadequate, frustrating the opportunity for recovery. Today's mental health care system is a patchwork relic—the result of disjointed reforms and policies. Instead of ready access to quality care, the system presents barriers that all too often add to the burden of mental illnesses for individuals, their families, and our communities.

The time has long passed for yet another piecemeal approach to mental health reform. Instead, the Commission recommends a fundamental transformation of the Nation's approach to mental health care. This transformation must ensure that mental health services and supports actively facilitate recovery, and build resilience to face life's challenges. Too often, today's system simply manages symptoms and accepts long-term disability. Building on the principles of the New Freedom Initiative, the recommendations we propose can improve the lives of millions of our fellow citizens now living with mental illnesses. The benefits will be felt across America in families, communities, schools, and workplaces.

The members of the Commission are gratified by your invitation to serve, are inspired by the innovative programs across America that we learned about, and are impressed by the readiness for change that we find in the mental health community. We look forward to the work ahead to make recovery from mental illness the expected outcome from a transformed system of care.

Sincerely,



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Executive Summary

VISION STATEMENT

We envision a future when everyone with a mental illness will recover, a future when mental illnesses can be prevented or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports – essentials for living, working, learning, and participating fully in the community.

In February 2001, President George W. Bush announced his New Freedom Initiative to promote increased access to educational and employment opportunities for people with disabilities. The Initiative also promotes increased access to assistive and universally designed technologies and full access to community life. Not since the Americans with Disabilities Act (ADA) — the landmark legislation providing protections against discrimination — and the Supreme Court's *Olmstead v. L.C.* decision, which affirmed the right to live in community settings, has there been cause for such promise and opportunity for full community participation for all people with disabilities, including those with psychiatric disabilities.

On April 29, 2002, the President identified three obstacles preventing Americans with mental illnesses from getting the excellent care they deserve:

- Stigma that surrounds mental illnesses,
- Unfair treatment limitations and financial requirements placed on mental health benefits in private health insurance, and
- The fragmented mental health service delivery system.

The President's New Freedom Commission on Mental Health (called *the Commission* in this report) is a key component of the New Freedom Initiative. The President launched the Commission to address the problems in the current mental health service delivery system that allow Americans to fall through the system's cracks.

In his charge to the Commission, the President directed its members to study the problems and gaps in the mental health system and make concrete recommendations for immediate improvements that the Federal government, State governments, local agencies, as well as public and private health care providers, can implement. Executive Order 13263 detailed the instructions to the Commission. (*See the Appendix.*)

The Commission's findings confirm that there are unmet needs and that many barriers impede care for people with mental illnesses. Mental illnesses are shockingly common; they affect almost every American family. It can happen to a child,* a

* In this *Final Report*, whenever *child* or *children* is used, it is understood that parents or guardians should be included in the process of making choices and decisions for minor children. This allows the family to provide support and guidance when developing relationships with mental health

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brother, a grandparent, or a co-worker. It can happen to someone from any background — African American, Alaska Native, Asian American, Hispanic American, Native American, Pacific Islander, or White American. It can occur at any stage of life, from childhood to old age. No community is unaffected by mental illnesses; no school or workplace is untouched.

In any given year, about 5% to 7% of adults have a serious mental illness, according to several nationally representative studies.[1-3] A similar percentage of children — about 5% to 9% — have a serious emotional disturbance. These figures mean that millions of adults and children are disabled by mental illnesses every year.[1; 4]

President Bush said,

> "... Americans must understand and send this message: mental disability is not a scandal – it is an illness. And like physical illness, it is treatable, especially when the treatment comes early."

Over the years, science has broadened our knowledge about mental health and illnesses, showing the potential to improve the way in which mental health care is provided. The U.S. Department of Health and Human Services (HHS) released *Mental Health: A Report of the Surgeon General*,[5] which reviewed scientific advances in our understanding of mental health and mental illnesses. However, despite substantial investments that have enormously increased the scientific knowledge base and have led to developing many effective treatments, many Americans are not benefiting from these investments.[6; 7]

Far too often, treatments and services that are based on rigorous clinical research languish for years rather than being used effectively at the earliest oppoftunity. For instance, according to the Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, the lag between discovering effective forms of treatment and incorporating them into routine patient care is unnecessarily long, lasting about 15 to 20 years.[8]

In its report, the Institute of Medicine (IOM) described a strategy to improve the quality of health care during the coming decade, including priority areas for refinement.[9] These documents, along with other recent publications and research findings, provide insight into the importance of mental heath, particularly as it relates to overall health.

In this *Final Report* ...

Adults with a serious mental illness are persons age 18 and over, who currently or at any time during the past year, have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-III-R *(Diagnostic and Statistical Manual for Mental Disorders)*[10], that has resulted in functional impairment[b] which substantially interferes with or limits one or more major life activities.

A serious emotional disturbance is defined as a mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified in the DSM-III-R that results in functional impairment that substantially interferes with or limits one or more major life activities in an individual up to 18 years of age. Examples of functional impairment that adversely affect educational performance include an inability to learn that cannot be explained by intellectual, sensory, or health factors; an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; inappropriate types of behavior or feelings under normal circumstances; a general pervasive mood of unhappiness or depression; or a tendency to develop physical symptoms or fears associated with personal or school problems.[11]

professionals, community resource representatives, teachers, and anyone else the individual or family invites. This same support and guidance can also include family members for individuals older than 18 years of age.

[b] *Functional impairment* is defined as difficulties that substantially interfere with or limit role functioning in one or more major life activities, including basic daily living skills (e.g., eating, bathing, dressing); instrumental living skills (e.g., maintaining a household, managing money, getting around the community, taking prescribed medication); and functioning in social, family, and vocational/educational contexts (Section 1912 (c) of the Public Health Services Act, as amended by Public Law 102-321).

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Mental Illnesses Presents Serious Health Challenges

Mental illnesses rank first among illnesses that cause disability in the United States, Canada, and Western Europe.[12] This serious public health challenge is under-recognized as a public health burden. In addition, one of the most distressing and preventable consequences of undiagnosed, untreated, or under-treated mental illnesses is suicide. The World Health Organization (WHO) recently reported that suicide worldwide causes more deaths every year than homicide or war .[13]

In addition to the tragedy of lost lives, mental illnesses come with a devastatingly high financial cost. In the U.S., the annual economic, indirect cost of mental illnesses is estimated to be $79 billion. Most of that amount — approximately $63 billion — reflects the loss of productivity as a result of illnesses. But indirect costs also include almost $12 billion in mortality costs (lost productivity resulting from premature death) and almost $4 billion in productivity losses for incarcerated individuals and for the time of those who provide family care.[14]

In 1997, the latest year comparable data are available, the United States spent more than $1 trillion on health care, including almost $71 billion on treating mental illnesses. Mental health expenditures are predominantly publicly funded at 57%, compared to 46% of overall health care expenditures. Between 1987 and 1997, mental health spending did not keep pace with general health care because of declines in private health spending under managed care and cutbacks in hospital expenditures.[15]

In 1997, the United States spent more than $1 trillion on health care, including almost $71 billion on treating mental illnesses.

The Current Mental Health System Is Complex

In its *Interim Report to the President*, the Commission declared, "... the mental health delivery system is fragmented and in disarray ... lead[ing] to unnecessary and costly disability, homelessness, school failure and incarceration." The report described the extent of unmet needs and barriers to care, including:

- Fragmentation and gaps in care for children,
- Fragmentation and gaps in care for adults with serious mental illnesses,
- High unemployment and disability for people with serious mental illnesses,
- Lack of care for older adults with mental illnesses, and
- Lack of national priority for mental health and suicide prevention.

The *Interim Report* concluded that the system is not oriented to the single most important goal of the people it serves — the hope of recovery. State-of-the-art treatments, based on decades of research, are not being transferred from research to community settings. In many communities, access to quality care is poor, resulting in wasted resources and lost opportunities for recovery. More individuals could recover from even the most serious mental illnesses if they had access in their communities to treatment and supports that are tailored to their needs.

The Commission recognizes that thousands of dedicated, caring, skilled providers staff and manage the service delivery system. The Commission does not attribute the shortcomings and failings of the contemporary system to a lack of professionalism or compassion of mental health care workers. Rather, problems derive principally from the manner in which the Nation's community-based mental health system has evolved over the past four to five decades. In short, the Nation must replace unnecessary institutional care with efficient, effective

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community services that people can count on. It needs to integrate programs that are fragmented across levels of government and among many agencies.

Building on the research literature and comments from more than 2,300 consumers,[c] family members, providers, administrators, researchers, government officials, and others who provided valuable insight into the way mental health care is delivered, after its yearlong study, the Commission concludes that traditional reform measures are not enough to meet the expectations of consumers and families.

To improve access to quality care and services, the Commission recommends fundamentally transforming how mental health care is delivered in America. The goals of this fundamental change are clear and align with the direction that the President established.

To improve access to quality care and services, the Commission recommends fundamentally transforming how mental health care is delivered in America.

The Goal of a Transformed System: Recovery

To achieve the promise of community living for everyone, new service delivery patterns and incentives must ensure that every American has easy and continuous access to the most current treatments and best support services. Advances in research, technology, and our understanding of how to treat mental illnesses provide powerful means to transform the system. In a transformed system, consumers and family members will have access to timely and accurate information that promotes learning, self-monitoring, and accountability. Health care providers will rely on up-to-date knowledge to provide optimum care for the best outcomes.

When a serious mental illness or a serious emotional disturbance is first diagnosed, the health care provider — in full partnership with consumers and families — will develop an individualized plan of care for managing the illness. This partnership of personalized care means basically choosing *who*, *what*, and *how* appropriate health care will be provided:

- Choosing which mental health care professionals are on the team,
- Sharing in decision making, and
- Having the option to agree or disagree with the treatment plan.

The highest quality of care and information will be available to consumers and families, regardless of their race, gender, ethnicity, language, age, or place of residence. Because recovery will be the common, recognized outcome of mental health services, the stigma surrounding mental illnesses will be reduced, reinforcing the hope of recovery for every individual with a mental illness.

In this *Final Report* ...

Stigma refers to a cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid, and discriminate against people with mental illnesses. Stigma is widespread in the United States and other Western nations.[16] Stigma leads others to avoid living, socializing, or working with, renting to, or employing people with mental disorders – especially severe disorders, such as schizophrenia. It leads to low self-esteem, isolation, and hopelessness. It deters the public from seeking and wanting to pay for care.[5] Responding to stigma, people with mental health problems internalize public attitudes and become so embarrassed or ashamed that they often conceal symptoms and fail to seek treatment.

As more individuals seek help and share their stories with friends and relatives, compassion will be the response, not ridicule.

[c] In this *Final Report*, *consumer* identifies people who use or have used mental health services (also known as mental health consumers, survivors, patients, or clients).

Successfully transforming the mental health service delivery system rests on two principles:

- **First, services and treatments must be consumer and family centered**, geared to give consumers real and meaningful choices about treatment options and providers — not oriented to the requirements of bureaucracies.

- **Second, care must focus on increasing consumers' ability to successfully cope with life's challenges, on facilitating recovery, and on building resilience**, not just on managing symptoms.

Built around consumers' needs, the system must be seamless and convenient.

In this *Final Report* ...

Recovery refers to the process in which people are able to live, work, learn, and participate fully in their communities. For some individuals, recovery is the ability to live a fulfilling and productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms. Science has shown that having hope plays an integral role in an individual's recovery.

Resilience means the personal and community qualities that enable us to rebound from adversity, trauma, tragedy, threats, or other stresses – and to go on with life with a sense of mastery, competence, and hope. We now understand from research that resilience is fostered by a positive childhood and includes positive individual traits, such as optimism, good problem-solving skills, and treatments. Closely-knit communities and neighborhoods are also resilient, providing supports for their members.

Transforming the system so that it will be both consumer and family centered and recovery-oriented in its care and services presents invigorating challenges. Incentives must change to encourage continuous improvement in agencies that provide care. New, relevant research findings must be systematically conveyed to front-line providers so that they can be applied to practice quickly. Innovative strategies must inform researchers of the unanswered questions of consumers, families, and providers. Research and treatment must recognize both the commonalities and the differences among Americans and must offer approaches that are sensitive to our diversity. Treatment and services that are based on proven effectiveness and consumer preference — not just on tradition or outmoded regulations — must be the basis for reimbursements.

The Nation must invest in the infrastructure to support emerging technologies and integrate them into the system of care. This new technology will enable consumers to collaborate with service providers, assume an active role in managing their illnesses, and move more quickly toward recovery.

The Commission identified the following six goals as the foundation for transforming mental health care in America. The goals are intertwined. No single step can achieve the fundamental restructuring that is needed to transform the mental health care delivery system.

GOALS

In a Transformed Mental Health System ...

GOAL 1	Americans Understand that Mental Health Is Essential to Overall Health.
GOAL 2	Mental Health Care Is Consumer and Family Driven.
GOAL 3	Disparities in Mental Health Services Are Eliminated.
GOAL 4	Early Mental Health Screening, Assessment, and Referral to Services Are Common Practice.
GOAL 5	Excellent Mental Health Care Is Delivered and Research Is Accelerated.
GOAL 6	Technology Is Used to Access Mental Health Care and Information.

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Achieving these goals will transform mental health care in America.

The following section of this report gives an overview of each goal of the transformed system, as well as the Commission's recommendations for moving the Nation toward achieving it. In the remainder of this report, the Commission discusses each goal in depth, showcasing model programs to illustrate the goal in practice and providing specific recommendations needed to transform the mental health system in America.

GOAL 1 Americans Understand that Mental Health Is Essential to Overall Health.

In a transformed mental health system, Americans will seek mental health care when they need it — with the same confidence that they seek treatment for other health problems. As a Nation, we will take action to ensure our health and well being through learning, self-monitoring, and accountability. We will continue to learn how to achieve and sustain our mental health.

The stigma that surrounds mental illnesses and seeking care for mental illnesses will be reduced or eliminated as a barrier. National education initiatives will shatter the misconceptions about mental illnesses, thus helping more Americans understand the facts and making them more willing to seek help for mental health problems. Education campaigns will also target specific audiences, including:

- Rural Americans who may have had little exposure to the mental health service system,
- Racial and ethnic minority groups who may hesitate to seek treatment in the current system, and
- People whose primary language is not English.

When people have a personal understanding of the facts, they will be less likely to stigmatize mental illnesses and more likely to seek help for mental health problems. The actions of reducing stigma, increasing awareness, and encouraging treatment will create a positive cycle that leads to a healthier population. As a Nation, we will also understand that good mental health can have a positive impact on the course of other illnesses, such as cancer, heart disease, and diabetes.

Improving services for individuals with mental illnesses will require paying close attention to how mental health care and general medical care systems work together. While mental health and physical health are clearly connected, the transformed system will provide collaborative care to bridge the gap that now exists.

Effective mental health treatments will be more readily available for most common mental disorders and will be better used in primary care settings. Primary care providers will have the necessary time, training, and resources to appropriately treat mental health problems. Informed consumers of mental health service will learn to recognize and identify their symptoms and will seek care without the fear of being disrespected or stigmatized. Older adults, children and adolescents, individuals from ethnic minority groups, and uninsured or low-income patients who are treated in public health care settings will receive care for mental disorders.

Understanding that mental health is essential to overall health is fundamental for establishing a health system that treats mental illnesses with the same urgency as it treats physical illnesses.

The transformed mental health system will rely on multiple sources of financing with the flexibility to pay for effective mental health treatments and services. This is a basic principle for a recovery-oriented system of care.

To aid in transforming the mental health system, the Commission makes two recommendations:

1.1 Advance and implement a national campaign to reduce the stigma of seeking care and a national strategy for suicide prevention.

1.2 Address mental health with the same urgency as physical health.

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GOAL 2 Mental Health Care Is Consumer and Family Driven.

In a transformed mental health system, a diagnosis of a serious mental illness or a serious emotional disturbance will set in motion a well-planned, coordinated array of services and treatments defined in a single plan of care. This detailed roadmap — a personalized, highly individualized health management program — will help lead the way to appropriate treatment and supports that are oriented toward recovery and resilience. Consumers, along with service providers, will actively participate in designing and developing the systems of care in which they are involved.

An individualized plan of care will give consumers, families of children with serious emotional disturbances, clinicians, and other providers a valid opportunity to construct and maintain meaningful, productive, and healing relationships. Opportunities for updates — based on changing needs across the stages of life and the requirement to review treatment plans regularly — will be an integral part of the approach. The plan of care will be at the core of the consumer-centered, recovery-oriented mental health system. The plan will include treatment, supports, and other assistance to enable consumers to better integrate into their communities; it will allow consumers to realize improved mental health and quality of life.

In partnership with their health care providers, consumers and families will play a larger role in managing the funding for their services, treatments, and supports. Placing financial support increasingly under the management of consumers and families will enhance their choices. By allowing funding to follow consumers, incentives will shift toward a system of learning, self-monitoring, and accountability. This program design will give people a vested economic interest in using resources wisely to obtain and sustain recovery.

The transformed system will ensure that needed resources are available to consumers and families. The burden of coordinating care will rest on the system, not on the families or consumers who are already struggling because of a serious illness. Consumers' needs and preferences will drive the types and mix of services provided, considering the gender, age, language, development, and culture of consumers.

The plan of care will be at the core of the consumer-centered, recovery-oriented mental health system.

To ensure that needed resources are available to consumers and families in the transformed system, States will develop a comprehensive mental health plan to outline responsibility for coordinating and integrating programs. The State plan will include consumers and families and will create a new partnership among the Federal, State, and local governments. The plan will address the full range of treatment and support service programs that mental health consumers and families need.

In exchange for this accountability, States will have the flexibility to combine Federal, State, and local resources in creative, innovative, and more efficient ways, overcoming the bureaucratic boundaries between health care, employment supports, housing, and the criminal justice systems.

Increased flexibility and stronger accountability will expand the choices and the array of services and supports available to attain the desired outcomes. Creative programs will be developed to respond to the needs and preferences of consumers and families, as reflected in their individualized plans of care.

Giving consumers the ability to participate fully in their communities will require a few essentials:

- Access to health care,
- Gainful employment opportunities,
- Adequate and affordable housing, and
- The assurance of not being unjustly incarcerated.

Strong leadership will need to:

- Align existing programs to deliver services effectively,
- Remove disincentives to employment (such as loss of financial benefits or having to choose between employment and health care), and
- Provide for a safe place to live.

In this transformed system, consumers' rights will be protected and enhanced. Implementing the 1999 *Olmstead v. L.C* decision in all States will allow services to be delivered in the most integrated setting possible — services in communities rather than in institutions. And services will be readily available so that consumers no longer face unemployment, homelessness, or incarceration because of untreated mental illnesses.

No longer will parents forgo the mental health services that their children desperately need. No longer will loving, responsible American parents face the dilemma of trading custody for care. Families will remain intact. Issues of custody will be separated from issues of care.

In this transformed system, stigma and discrimination against people with mental illnesses will not have an impact on securing health care, productive employment, or safe housing. Our society will not tolerate employment discrimination against people with serious mental illnesses — in either the public or private sector.

Consumers' rights will be protected concerning the use of seclusion and restraint. Seclusion and restraint will be used only as safety interventions of last resort, not as treatment interventions. Only licensed practitioners who are specially trained and qualified to assess and monitor consumers' safety and the significant medical and behavioral risks inherent in using seclusion and restraint will be able to order these interventions.

The hope and the opportunity to regain control of their lives —often vital to recovery — will become real for consumers and families. Consumers will play a significant role in shifting the current system to a recovery-oriented one by participating in planning, evaluation, research, training, and service delivery.

To aid in transforming the mental health system, the Commission makes five recommendations:

2.1 Develop an individualized plan of care for every adult with a serious mental illness and child with a serious emotional disturbance.

2.2 Involve consumers and families fully in orienting the mental health system toward recovery.

2.3 Align relevant Federal programs to improve access and accountability for mental health services.

2.4 Create a Comprehensive State Mental Health Plan.

2.5 Protect and enhance the rights of people with mental illnesses.

GOAL 3 Disparities in Mental Health Services Are Eliminated.

In a transformed mental health system, all Americans will share equally in the best available services and outcomes, regardless of race, gender, ethnicity, or geographic location. Mental health care will be highly personal, respecting and responding to individual differences and backgrounds. The workforce will include members of ethnic, cultural, and linguistic minorities who are trained and employed as mental health service providers. People who live in rural and remote geographic areas will have access to mental health professionals and other needed resources. Advances in treatments will be available in rural and less populated areas. Research and training will continuously aid clinicians in understanding how to appropriately tailor interventions to the needs of consumers, recognizing factors such as age, gender, race, culture, ethnicity, and locale.

Services will be tailored for culturally diverse populations and will provide access, enhanced quality, and positive outcomes of care. American Indians, Alaska Natives, African Americans, Asian Americans, Pacific Islanders, and Hispanic Americans will not continue to bear a disproportionately high burden of disability from mental health disorders.[1] These populations will have accessible, available mental health services. They will receive the same high quality of care that all Americans receive. To develop culturally competent treatments, services, care, and support, mental health research will include these underserved populations. In addition, providers will include individuals who share and respect the beliefs, norms, values, and patterns of communication of culturally diverse populations.

In rural and remote geographic areas, service providers will be more readily available to help create a consumer-centered system. Using such tools as videoconferencing and telehealth, advances in treatments will be brought to rural and less populated areas of the country. These technologies will be used to provide care at the same time they break down the sense of isolation often experienced by consumers.

Mental health education and training will be provided to general health care providers, emergency room staff, and first responders, such as law enforcement personnel and emergency medical technicians, to overcome the uneven geographic distribution of psychiatrists, psychologists, and psychiatric social workers.

In a transformed mental health system, all Americans will share equally in the best available services and outcomes, regardless of race, gender, ethnicity, or geographic location.

To aid in transforming the mental health system, the Commission makes two recommendations:

3.1 Improve access to quality care that is culturally competent.

3.2 Improve access to quality care in rural and geographically remote areas.

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GOAL 4 Early Mental Health Screening, Assessment, and Referral to Services Are Common Practice.

In a transformed mental health system, the early detection of mental health problems in children and adults — through routine and comprehensive testing and screening — will be an expected and typical occurrence. At the first sign of difficulties, preventive interventions will be started to keep problems from escalating. For example, a child whose serious emotional disturbance is identified early will receive care, preventing the potential onset of a co-occurring substance use disorder and breaking a cycle that otherwise can lead to school failure and other problems.

Quality screening and early intervention will occur in both readily accessible, low-stigma settings, such as primary health care facilities and schools, and in settings in which a high level of risk exists for mental health problems, such as criminal justice, juvenile justice, and child welfare systems. Both children and adults will be screened for mental illnesses during their routine physical exams.

For consumers of all ages, early detection, assessment, and links with treatment and supports will help prevent mental health problems from worsening. Service providers across settings will also routinely screen for co-occurring mental illnesses and substance use disorders. Early intervention and appropriate treatment will also improve outcomes and reduce pain and suffering for children and adults who have or who are at risk for co-occurring mental and addictive disorders.

Early detection of mental disorders will result in substantially shorter and less disabling courses of impairment.

For consumers of all ages, early detection, assessment, and links with treatment and supports will help prevent mental health problems from worsening.

To aid in transforming the mental health system, the Commission makes four recommendations:

- **4.1 Promote the mental health of young children.**
- **4.2 Improve and expand school mental health programs.**
- **4.3 Screen for co-occurring mental and substance use disorders and link with integrated treatment strategies.**
- **4.4 Screen for mental disorders in primary health care, across the lifespan, and connect to treatment and supports.**

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GOAL 5 Excellent Mental Health Care Is Delivered and Research Is Accelerated.

In a transformed mental health system, consistent use of evidence-based, state-of-the art medications and psychotherapies will be standard practice throughout the mental health system. Science will inform the provision of services, and the experience of service providers will guide future research. Every time any American — whether a child or an adult, a member of a majority or a minority, from an urban or rural area — comes into contact with the mental health system, he or she will receive excellent care that is consistent with our scientific understanding of what works. That care will be delivered according to the consumer's individualized plan.

Research has yielded important advances in our knowledge of the brain and behavior, and helped develop effective treatments and service delivery strategies for many mental disorders. In a transformed system, research will be used to develop new evidence-based practices to prevent and treat mental illnesses. These discoveries will be immediately put into practice. Americans with mental illnesses will fully benefit from the enormous increases in the scientific knowledge base and the development of many effective treatments.

Also benefiting from these developments, the workforce will be trained to use the most advanced tools for diagnosis and treatments. Translating research into practice will include adequate training for front-line providers and professionals, resulting in a workforce that is equipped to use the latest breakthroughs in modern medicine. Research discoveries will become routinely available at the community level. To realize the possibilities of advances in treatment, and ultimately in prevention or a cure, the Nation will continue to invest in research at all levels.

Knowledge about evidence-based practices (the range of treatments and services of well-documented effectiveness), as well as emerging best practices (treatments and services with a promising but less thoroughly documented evidentiary base), will be widely circulated and used in a variety of mental health specialties and in general health, school-based, and other settings. Countless people with mental illnesses will benefit from improved consumer outcomes including reduced symptoms, fewer and less severe side effects, and improved functioning. The field of mental health will be encouraged to expand its efforts to develop and test new treatments and practices, to promote awareness of and improve training in evidence-based practices, and to better finance those practices.

Research discoveries will become routinely available at the community level.

The Nation will have a more effective system to identify, disseminate, and apply proven treatments to mental health care delivery. Research and education will play critical roles in the transformed mental health system. Advanced treatments will be available and adapted to individual preferences and needs, including language and other ethnic and cultural considerations. Investments in technology will also enable both consumers and providers to find the most up-to-date resources and knowledge to provide optimum care for the best outcomes. Studies will incorporate the unique needs of cultural, ethnic, and linguistic minorities and will help ensure full access to effective treatment for all Americans.

To aid in transforming the mental health system, the Commission makes four recommendations:

5.1 Accelerate research to promote recovery and resilience, and ultimately to cure and prevent mental illnesses.

5.2 Advance evidence-based practices using dissemination and demonstration projects and create a public-private partnership to guide their implementation.

5.3 Improve and expand the workforce providing evidence-based mental health services and supports.

5.4 Develop the knowledge base in four understudied areas: mental health disparities, long-term effects of medications, trauma, and acute care.

GOAL 6 Technology Is Used to Access Mental Health Care and Information.

In a transformed mental health system, advanced communication and information technology will empower consumers and families and will be a tool for providers to deliver the best care. Consumers and families will be able to regularly communicate with the agencies and personnel that deliver treatment and support services and that are accountable for achieving the goals outlined in the individual plan of care. Information about illnesses, effective treatments, and the services in their community will be readily available to consumers and families.

Access to information will foster continuous, caring relationships between consumers and providers by providing a medical history, allowing for self-management of care, and electronically linking multiple service systems. Providers will access expert systems that bring to bear the most recent breakthroughs and studies of optimal outcomes to facilitate the best care options. Having agreed to use the same health messaging standards, pharmaceutical codes, imaging standards, and laboratory test names, the Nation's health system will be much closer to speaking a common language and providing superior patient care. Informed consumers and providers will result in better outcomes and will more efficiently use resources.

Electronic health records can improve quality by promoting adoption and adherence to evidence-based practices through inclusion of clinical reminders, clinical practice guidelines, tools for clinical decision support, computer order entry, and patient safety alert systems. For example, prescription medications being taken or specific drug allergies would be known, which could prevent serious injury or death resulting from drug interactions, excessive dosages or allergic reactions.

Access to care will be improved in many underserved rural and urban communities by using health technology, telemedicine care, and consultations. Health technology and telehealth will offer a powerful means to improve access to mental health care in underserved, rural, and remote areas. The privacy of personal health information — especially in the case of mental illnesses — will be strongly protected and controlled by consumers and families. With appropriate privacy protection, electronic records will enable essential medical and mental health information to be shared across the public and private sectors.

Reimbursements will become flexible enough to allow implementing evidence-based practices and coordinating both traditional clinical care and e-health visits. In both the public and private sectors, policies will change to support these innovative approaches.

The privacy of personal health information — especially in the case of mental illnesses — will be strongly protected and controlled by consumers and families.

An integrated information technology and communications infrastructure will be critical to achieving the five preceding goals and transforming mental health care in America. To address this technological need in the mental health care system, this goal envisions two critical technological components:

- A robust telehealth system to improve access to care, and
- An integrated health records system and a personal health information system for providers and patients.

To aid in transforming the mental health system, the Commission makes two recommendations:

6.1 Use health technology and telehealth to improve access and coordination of mental health care, especially for Americans in remote areas or in underserved populations.

6.2 *Develop and implement integrated electronic* health record and personal health information systems.

Preventing mental illnesses remains a promise of the future. Granted, the best option is to avoid or delay the onset of any illness, but the Executive Order directed the Commission to conduct a comprehensive study of the delivery of mental health services. The Commission recognizes that it is better to prevent an illness than to treat it, but unmet needs and barriers to services must first be identified to reach the millions of Americans with existing mental illnesses who are deterred from seeking help. The barriers may exist for a variety of reasons:

- Stigma,
- Fragmented services,
- Cost,
- Workforce shortages,
- Unavailable services, and
- Not knowing where or how to get care.

These barriers are all discussed in this report.

The Commission — aware of all the limitations on resources — examined realigning Federal financing with a keen awareness of the constraints. As such, the policies and improvements recommended in this *Final Report* reflect policy and program changes that make the most of existing resources by increasing cost effectiveness and reducing unnecessary and burdensome regulatory barriers, coupled with a strong measure of accountability. A transformed mental health system will more wisely invest resources to provide optimal care while making the best use of limited resources.

The process of transforming mental health care in America drives the system toward a delivery structure that will give consumers broader discretion in how care decisions are made. This shift will give consumers more confidence to require that care be sensitive to their needs, that the best available treatments and supports be available, and that demonstrably effective technologies be widely replicated in different settings. This confidence will then enhance cooperative relationships with mental health care professionals who share the hope of recovery.

GOALS AND RECOMMENDATIONS

In a Transformed Mental Health System ...

GOAL 1 Americans Understand that Mental Health Is Essential to Overall Health.

RECOMMENDATIONS

1.1 Advance and implement a national campaign to reduce the stigma of seeking care and a national strategy for suicide prevention.

1.2 Address mental health with the same urgency as physical health.

GOAL 2 Mental Health Care Is Consumer and Family Driven.

RECOMMENDATIONS

2.1 Develop an individualized plan of care for every adult with a serious mental illness and child with a serious emotional disturbance.

2.2 Involve consumers and families fully in orienting the mental health system toward recovery.

2.3 Align relevant Federal programs to improve access and accountability for mental health services.

2.4 Create a Comprehensive State Mental Health Plan.

2.5 Protect and enhance the rights of people with mental illnesses.

GOAL 3 Disparities in Mental Health Services Are Eliminated.

RECOMMENDATIONS

3.1 Improve access to quality care that is culturally competent.

3.2 Improve access to quality care in rural and geographically remote areas.

GOAL 4 Early Mental Health Screening, Assessment, and Referral to Services Are Common Practice.

RECOMMENDATIONS

4.1 Promote the mental health of young children.

4.2 Improve and expand school mental health programs.

4.3 Screen for co-occurring mental and substance use disorders and link with integrated treatment strategies.

4.4 Screen for mental disorders in primary health care, across the life span, and connect to treatment and supports.

GOAL 5	**Excellent Mental Health Care Is Delivered and Research Is Accelerated.**		
	RECOMMENDATIONS	5.1	Accelerate research to promote recovery and resilience, and ultimately to cure and prevent mental illnesses.
		5.2	Advance evidence-based practices using dissemination and demonstration projects and create a public-private partnership to guide their implementation.
		5.3	Improve and expand the workforce providing evidence-based mental health services and supports.
		5.4	Develop the knowledge base in four understudied areas: mental health disparities, long-term effects of medications, trauma, and acute care.
GOAL 6	**Technology Is Used to Access Mental Health Care and Information.**		
	RECOMMENDATIONS	6.1	Use health technology and telehealth to improve access and coordination of mental health care, especially for Americans in remote areas or in underserved populations.
		6.2	Develop and implement integrated electronic health record and personal health information systems.

GOAL 1 Americans Understand that Mental Health Is Essential to Overall Health.

RECOMMENDATIONS

1.1 Advance and implement a national campaign to reduce the stigma of seeking care and a national strategy for suicide prevention.

1.2 Address mental health with the same urgency as physical health.

Understanding the Goal

Many People with Mental Illnesses Go Untreated

Too many Americans are unaware that mental illnesses can be treated and recovery is possible. In fact, a wide array of effective mental health services and treatments is available to allow children and adults to be vital contributors to their communities. Yet, too many people remain unserved, and the consequences can be shattering. Some people end up addicted to drugs or alcohol, on the streets and homeless, or in jail, prison, or juvenile detention facilities.

The World Health Organization (WHO) identified mental illnesses as the leading causes of disability worldwide. (*See Figure 1.1.*) This groundbreaking study found that mental illnesses (including depression, bipolar disorder, and schizophrenia) account for nearly 25% of all disability across major industrialized countries.[1,2]

As the President indicated in his speech announcing the Commission (Albuquerque, New Mexico, April 29, 2002),

> "Our country must make a commitment: Americans with mental illness deserve our understanding, and they deserve excellent care. They deserve a health system that treats their illness with the same urgency as a physical illness."

Unfortunately, several obstacles to achieving this goal remain. For example, stigma frequently surrounds mental illnesses, prompting many people to hide their symptoms and avoid treatment. Sadly, only 1 out of 2 people with a serious form of mental illness seeks treatment for the disorder.[2-4]

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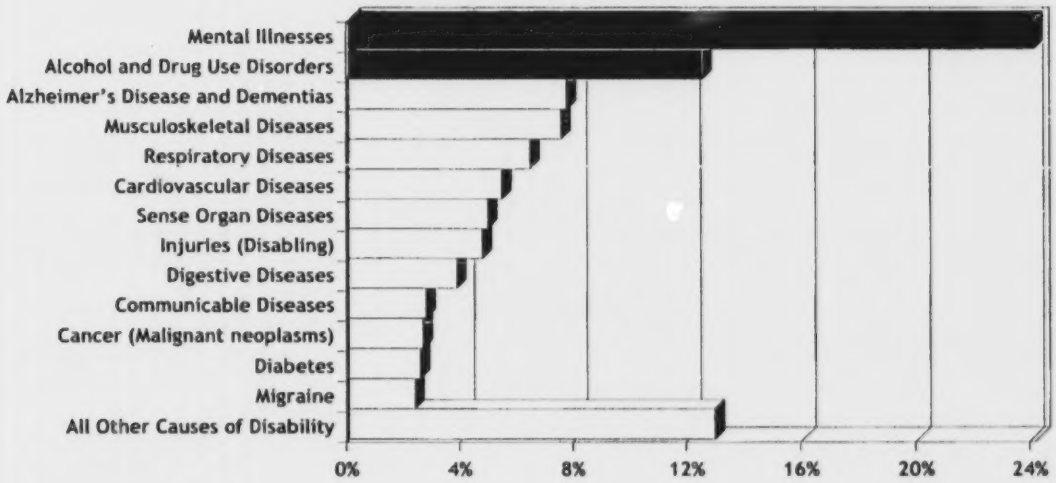
*FIGURE 1.1. Causes of Disability**
United States, Canada and Western Europe, 2000



* Causes of disability for all ages combined. Measures of disability are based on the number of years of "healthy" life lost with less than full health (i.e., YLD: years lost due to disability) for each incidence of disease, illness, or condition. All data shown add up to 100%.

Stigma Impedes People from Getting the Care They Need

Stigma is a pervasive barrier to understanding the gravity of mental illnesses and the importance of mental health. For instance, 61% of Americans think that people with schizophrenia are likely to be dangerous to others.[17] However, in reality, these individuals are rarely violent. If they are violent, the violence is usually tied to substance abuse.[18]

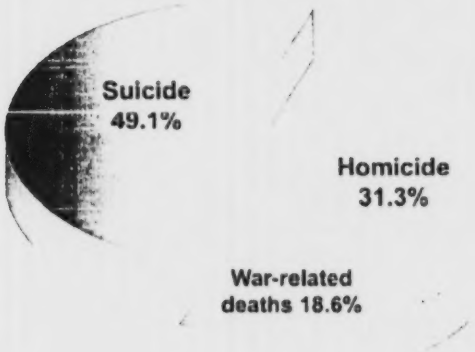
Stigma is a pervasive barrier to understanding the gravity of mental illnesses and the importance of mental health.

Some people may not recognize or correctly identify their symptoms of mental illness; when they do recognize them, they may be reluctant to seek care because of stigma.[19; 20] Stigma is particularly pronounced among older adults, ethnic and racial minorities, and residents of rural areas.[1]

Suicide Presents Serious Challenges

Suicide is a serious public health challenge that has not received the attention and degree of national priority it deserves. Many Americans are unaware of suicide's toll and its global impact. It is the leading cause of violent deaths worldwide, outnumbering homicide or war-related deaths.[13] *(See Figure 1.2.)*

FIGURE 1.2.
Suicide Is the Leading Cause of Violent Deaths Worldwide



In the U.S., suicide claims approximately 30,000 lives each year. Overall, suicide was the 11th leading cause of death among Americans in 2000.[21] In 1999, more than 152,000 hospital admissions and more than 700,000 visits to hospital emergency rooms were for self-harming behaviors.[22] The vast majority of all people who die by suicide have a mental illness — often undiagnosed or untreated.[21]

Suicide was also the fourth leading cause of death among youth aged 10-14, third among those between 15 and 24, second among 25- to 34-year olds, and fourth among those 35-44 years in 1999.[23] The rate of suicide is highest among older men, compared with all other age groups. But alarmingly, the rate of teen suicide (for those from ages 15 to 19) has tripled since the 1950s.[21]

Better Coordination Is Needed Between Mental Health Care and Primary Health Care

Research demonstrates that mental health is key to overall physical health.[24-26] Therefore, improving services for individuals with mental illnesses requires paying close attention to how mental health care and general medical care interact. While mental health and physical health are clearly connected, a chasm exists between the mental health care and general health care systems in financing and practice. Primary care providers may lack the necessary time, training, or resources to provide appropriate treatment for mental health problems.

> Mental health is key to overall physical health.

Mental disorders frequently co-exist with other medical disorders. For example, a number of studies have shown that adults with common medical disorders have high rates of depression and anxiety.[27-29] Depression is also common in people with coronary heart disease and other cardiac illnesses. This situation is especially dangerous because depression increases the risk of dying from heart disease by as much as three-fold.[30; 31] Depression impairs self-care and adherence to treatments for chronic medical illnesses.[32] Similarly, people with both diabetes and depression have a greater likelihood of experiencing a greater number of diabetes complications compared to those without depression.[33]

Mental Health Financing Poses Challenges

Insurance plans that place greater restrictions on treating mental illnesses than on other illnesses prevent some individuals from getting the care that would dramatically improve their lives. Mental health benefits have traditionally been more limited than other medical benefits.

The Commission strongly supports the President's call for Federal legislation to provide full parity between insurance coverage for mental health care and for physical health care.

States have relied on the Medicaid program to support their mental health systems. As a result, Medicaid is now the largest payer of mental health services in the country.

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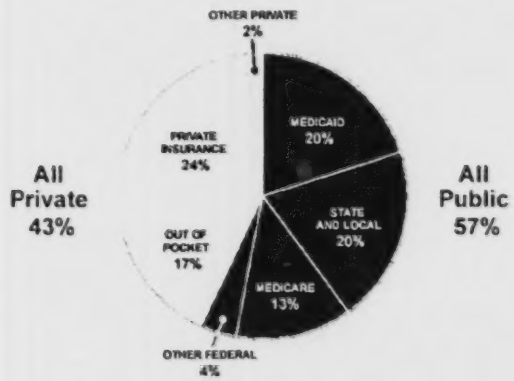
Studies show that 20% to 25% of services for non-elderly adult users of mental health are funded only by Medicaid. Between 7% and 13% of Medicaid enrollees are mental health service users. By 1997, Medicaid spent more than $14 billion that accounted for 20% of all mental health spending and 36% of all public mental health spending in the United States.[15; 34; 35] *(See Figure 1.3.)* Although States have used Medicaid as a primary source of funding, missed opportunities exist because States are often uncertain about:

- How to cover evidence-based practices,
- Which services may be covered under the traditional State plan,
- Which services are allowable under waiver, and
- How to use Medicaid funds seamlessly with other private sources.

FIGURE 1.3.
Distribution of Public and Private Mental Health Expenditures, 1997



Also, many older adults and disabled individuals may rely on Medicare for their health care. However, in this program, coverage is an issue — with the most obvious example being the lack of a prescription drug benefit. As important as Medicaid and Medicare have been, they have not always grown along with the dramatic improvements in health care, such as prescription drugs, preventive care, and coordination of care. Action is needed now to remedy this problem.

Services and Funding Are Fragmented Across Several Programs

To add to the problem, services and funding are fragmented across different programs. Increasingly, multiple programs with disparate objectives and requirements finance services and supports for those with mental illnesses including:

- State and local general fund appropriations,
- Medicare,
- Social Security (Social Security Income/ Social Security and Disability Income payments),
- Vocational rehabilitation,
- Education,
- Temporary Assistance for Needy Families (TANF),
- Juvenile justice and criminal justice,
- Child welfare, and
- Federal block grants.

While each program provides essential assistance, together they create a financing approach that is complex, fragmented, and inconsistent in its coverage.

Financing Sources Can Be Restrictive

The current system of mental health care must rely on many sources of financing. Too many of those funding streams are tightly restricted in how they can be used or for whom. Providing access to effective treatments and services that are easy to navigate and that use flexible funding streams is crucial to transforming mental health care in America.

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Providing access to effective treatments and services that are easy to navigate and that use flexible funding streams is crucial to transforming mental health care in America.

Currently, eligibility requirements for receiving services or supports and reimbursement policies vary widely, and States must rely on waivers to provide treatments and supports that Federal standards deem optional. If the mental health care system is to be responsive to the unique needs of consumers, then it must be flexible enough to accommodate each person. Our treatment systems should be able to serve consumers who are uninsured or who need a service that isn't covered by their insurer. Steps must be taken to improve the flexibility and accountability of financing in both private insurance and public programs.

Achieving the Goal

RECOMMENDATION 1.1 **Advance and implement a national campaign to reduce the stigma of seeking care and a national strategy for suicide prevention.**

Public Education Activities Can Help Encourage People to Seek Treatment

Research findings support the connection between good mental health and overall personal health.[24-26] Increasing public understanding that mental health is an essential and an integral part of overall health can lead to improved services, more balanced policy decisions, and a healthier Nation.

Increasing public understanding about mental health and mental illnesses requires action at every level of government and in the private sector. The first step is to reduce the stigma surrounding mental illnesses, using targeted public education activities that are designed to provide the public with factual information about mental illnesses and to suggest strategies for enhancing mental health, much like anti-smoking campaigns promote physical health.

Research shows that the most effective way to reduce stigma is through personal contact with someone with a mental illness.[36] The U.S. Department of Health and Human Services (HHS) has incorporated this research finding into its new campaign targeted to men, *Real Men. Real Depression.* Through compelling personal stories told through television, video, the Internet, and print media, the campaign encourages men to recognize depression and its impact on their work, home, and community life. For America to move forward in addressing the seriousness of mental health issues, the public must understand that these mental conditions are illnesses that can be reliably diagnosed and effectively treated.

Research shows that the most effective way to reduce stigma is through personal contact with someone with a mental illness.

Targeted public education can increase awareness about the effectiveness of mental health services and can encourage people to seek treatment, thus reducing the stigma and discrimination associated with mental illnesses. Eliminating stigma will also help reduce the isolation of these individuals from society.

Media-oriented and other types of mental health awareness campaigns can inform the public about

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where and *how* to obtain help. Collaboration between the public and private sectors and close coordination with consumers and other stakeholders is encouraged to reduce the possibility of sending mixed messages or duplicated messages to the public.

Campaigns should use a multi-faceted approach that includes various public education strategies, as well as direct, consumer-to-target audience, interpersonal contact methods, such as dialog meetings and speakers' bureaus. The campaigns should also address and promote the themes of recovery and the positive societal contributions that people with mental illnesses make, correcting the misperceptions associated with these illnesses.

By increasing the public's understanding that mental illnesses are treatable and recovery is possible, stigma and discrimination will be reduced for people with mental illnesses.

The Commission recommends that the Substance Abuse and Mental Health Services Administration (SAMHSA) and National Institutes of Health (NIH) take the lead to coordinate and develop targeted public education initiatives to increase understanding of mental illnesses and to encourage help-seeking behaviors. By increasing the public's understanding that mental illnesses are treatable and recovery is possible, stigma and discrimination will be reduced for people with mental illnesses. In addition, this change of attitude is important because screening and identifying mental illnesses are of little value unless the person with the problem is willing to accept the care that may be offered.

Swift Action Is Needed to Prevent Suicide

The urgent need for action on suicide prevention is the subject of a number of recent reports and congressional resolutions. For example, just last year the Institute of Medicine (IOM) underscored suicide prevention as a significant public health problem with the publication *Reducing Suicide: A National Imperative*.[21]

As another example, through its pioneering program on suicide prevention, the U.S. Air Force works to reverse deep-seated attitudes in the military that seeking help should be avoided and is shameful. (*See Figure 1.4.*) The program helps the target audience — in this case Air Force personnel — recognize that it takes courage to confront life's stresses and that taking steps to do so is "career-enhancing."

In addition, the National Strategy for Suicide Prevention (NSSP) was developed and launched through the combined work of advocates, clinicians, researchers, and survivors around the Nation.[37] It is the first attempt in the United States to prevent suicide through such a coordinated approach. The NSSP lays out a suicide prevention framework for action and guides development of an array of services and programs. It requires involving a variety of organizations and individuals and emphasizes coordinating resources and delivering culturally appropriate services at all levels of a public-private partnership. This promising blueprint for change is poised to guide the Nation toward a brighter future for suicide prevention.

The Commission urges swiftly implementing and enhancing the NSSP to serve as a blueprint for communities and all levels of government. Within the public education component of this initiative, the messages should encourage the target audiences to seek help for mental health problems and to understand that suicide is preventable. Public education efforts should also be targeted to distinct and often hard-to-reach populations, such as ethnic and racial minorities, older men, and adolescents.

FIGURE 1.4. MODEL PROGRAM: Suicide Prevention and Changing Attitudes About Mental Health Care

Program	Air Force Initiative to Prevent Suicide
Goal	To reduce the alarming rate of suicide. Between 1990 and 1994, one in every four deaths among active duty U.S. Air Force personnel was from suicide. After unintentional injuries, suicide was the second leading cause of death in the Air Force.
Features	In 1996, the Air Force Chief of Staff initiated a community-wide approach to prevent suicide through hard-hitting messages to all active duty personnel. The messages recognized the courage of those confronting life's stresses and encouraged them to seek help from mental health clinics — actions that were once regarded as career hindering, but were now deemed "career-enhancing." Other features of the program: education and training, improved surveillance, critical incident stress management, and integrated delivery systems of care.
Outcomes	From 1994 to 1998, the suicide rate dropped from 16.4 to 9.4 suicides per 100,000. By 2002, the overall decline from 1994 was about 50%. Researchers also found significant declines in violent crime, family violence, and deaths that resulted from unintentional injuries.[38] Air Force leaders have emphasized community-wide involvement in every aspect of the project.
Biggest challenge	Sustaining the enthusiasm by service providers as the program has become more established.
How other organizations can adopt	The program can be transferred to any community that has identified leaders and organization, especially other military services, large corporations, police forces, firefighters, schools, and universities.
Sites	All U.S. Air Force locations throughout the world

Further, the Commission recommends forming a national level public-private partnership to advance the goals and objectives of the NSSP that proposes local projects in every State. This public-private partnership would emphasize building voluntary coalitions to address suicide prevention in communities and would include local leaders, business and school personnel, and representatives of the faith community.

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RECOMMENDATION **1.2 Address mental health with the same urgency as physical health.**

Recognize the Connection Between Mental Health and Physical Health

Health care and other human service systems should treat adults with serious mental illnesses and children with serious emotional disturbances with the same dignity, urgency, and quality of care that is given to people with any other form of illness. Doing so can contribute greatly to reducing stigma while encouraging people in need to seek help.

Good mental health improves the quality of life for people with serious physical illnesses and may contribute to longer life in general. When considering older adults who have general medical illnesses — such as heart disease, stroke, cancer, and arthritis — about 25% also have depression.[39-44] Depression is associated with a shortened life expectancy.[30; 31]

The Commission recommends reviewing existing scientific literature and initiating new studies to examine the impact of mental health and mental illnesses on physical illnesses and health. It is anticipated that reviewing the current scientific knowledge in this critical area will contribute significantly to identifying new research priorities. New studies should focus on innovative and effective ways to enhance the balance between mental and physical health. These studies should also support using best practices to improve quality of life, provide effective treatment, and enhance cost-effectiveness.

Good mental health improves the quality of life for people with serious physical illnesses and may contribute to longer life in general.

Address Unique Needs of Mental Health Financing

As future opportunities emerge to transform health care in America, mental health care must be considered part of the reform necessary to achieve optimal health benefits for the American public.

The Commission recommends including issues of critical importance for mental health service delivery as part of the national dialog on health care reform. The two largest Federal health care programs — Medicare and Medicaid — as well as private insurance programs must address the delivery of mental health care. Any effort to strengthen or improve the Medicare and Medicaid programs should offer beneficiaries options to effectively use the most up-to-date treatments and services. Critical issues to be addressed include:

- Prescription drug coverage,
- Accessibility of services,
- Affordability of services,
- Clarification of coordination of benefits between the Medicare and Medicaid programs,
- Support for evidenced-based services and supports,
- Support for self-direction,
- Choice of health care services and resources, and
- Outcomes and accountability.

To be effective and comprehensive, mental health care must rely on many sources of financing. Flexible, accountable financing that pays for treatments and services that work and result in recovery is an essential aspect of transforming mental health care in America.

GOAL 2 Mental Health Care Is Consumer and Family Driven.

RECOMMENDATIONS

2.1 Develop an individualized plan of care for every adult with a serious mental illness and child with a serious emotional disturbance.

2.2 Involve consumers and families fully in orienting the mental health system toward recovery.

2.3 Align relevant Federal programs to improve access and accountability for mental health services.

2.4 Create a Comprehensive State Mental Health Plan.

2.5 Protect and enhance the rights of people with mental illnesses.

Understanding the Goal

The Complex Mental Health System Overwhelms Many Consumers

Nearly every consumer of mental health services who testified before or submitted public comments to the Commission expressed the need to fully participate in his or her plan for recovery. In the case of children with serious emotional disturbances, their parents and guardians strongly echoed this sentiment. Consumers and families told the Commission that having hope and the opportunity to regain control of their lives was vital to their recovery.

Indeed, emerging research has validated that hope and self-determination are important factors contributing to recovery.[45; 46] However, understandably, consumers often feel overwhelmed and bewildered when they must access and integrate mental health care, support services, and disability benefits across multiple, disconnected programs that span Federal, State, and local agencies, as well as the private sector.

As the President said in his speech announcing the creation of the Commission, one of the major obstacles to quality mental health care is:

> "... our fragmented mental health service delivery system. Mental health centers and hospitals, homeless shelters, the justice system, and our schools all have contact with individuals suffering from mental disorders."

Consumers of mental health services must stand at the *center* of the system of care. Consumers' needs must drive the care and services that are provided. Unfortunately, the services currently available to consumers are fragmented, driven by financing rules and regulations, and restricted by bureaucratic boundaries. They defy easy description.

Program Efforts Overlap

Loosely defined, the mental health care system collectively refers to the full array of programs for anyone with a mental illness. These programs exist at every level of government and throughout the private sector. They have varying missions, settings, and financing. They deliver or pay for treatments, services, or other types of supports, such as housing, employment, or disability benefits. For instance, one program's mission might be to offer treatment through medication, psychotherapy, substance abuse treatment, or counseling, while another program's purpose might be to offer rehabilitation support. The setting could be a hospital, a community clinic, a private office, a school, or a business.

Many mainstream social welfare programs are not designed to serve people with serious mental illnesses, even though this group has become one of the largest and most severely disabled groups of beneficiaries.

A brief look at traditional funding sources for mental health services illustrates the impact of this overly complex system. The Community Mental Health Services Block Grant, funded by the U.S. Department of Health and Human Services (HHS) through the Substance Abuse and Mental Health Services Administration (SAMHSA), provides funding to the 59 States and territories. It is only one source of Federal funding that State mental health authorities manage. The funding totaled approximately $433 million in 2002,[47] or less than 3% of the revenues of these State agencies.[48]

But larger Federal programs that are not focused on mental health care play a much more substantial role in financing it. For example, through Medicare and Medicaid programs alone, HHS spends nearly $24 billion each year on beneficiaries' mental health care.[15] Moreover, the largest Federal program that supports people with mental illnesses is not even a health services program — the Social Security Administration's Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) programs, with payments totaling approximately $21 billion in 2002.[49-51]

Other significant programs that are funded separately and play a role in State and local systems include:

- Housing,
- Rehabilitation,
- Education,
- Child welfare,
- Substance abuse,
- General health,
- Criminal justice, and
- Juvenile justice, among others.

Each program has its own complex, sometimes contradictory, set of rules. Many mainstream social welfare programs are not designed to serve people with serious mental illnesses, even though this group has become one of the largest and most severely disabled groups of beneficiaries.

If this current system worked well, it would function in a coordinated manner, and it would deliver the best possible treatments, services, and supports. However, as it stands, the current system often falls short. Many people with serious mental illnesses and children with serious emotional disturbances remain homeless or housed in institutions, jails, or juvenile detention centers. These individuals are unable to participate in their own communities.

Consumers and Families Do Not Control Their Own Care

In a consumer- and family-driven system, consumers choose their own programs and the providers that will help them most. Their needs and preferences drive the policy and financing decisions that affect them. Care is consumer-centered, with providers working in full partnership with the consumers they serve to develop individualized plans of care. Individualized plans of care help overcome the problems that result from fragmented or uncoordinated services and systems.

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Currently, adults with serious mental illnesses and parents of children with serious emotional disturbances typically have limited influence over the care they or their children receive. Increasing opportunities for consumers to choose their providers and allowing consumers and families to have greater control over funds spent on their care and supports facilitate personal responsibility, create an economic interest in obtaining and sustaining recovery, and shift the incentives towards a system that promotes learning, self-monitoring, and accountability. Increasing choice protects individuals and encourages quality.

Individualized plans of care help overcome the problems that result from fragmented or uncoordinated services and systems.

Evidence shows that offering a full range of community-based alternatives is more effective than hospitalization and emergency room treatment.[18] Without choice and the availability of acceptable treatment options, people with mental illnesses are unlikely to engage in treatment or to participate in appropriate and timely interventions. Thus, giving consumers access to a range of effective, community-based treatment options is critical to achieving their full community participation. To ensure this access, the array of community-based treatment options must be expanded.

In particular, community-based treatment options for children and youth with serious emotional disorders must be expanded. Creating alternatives to inpatient treatment improves engagement in community-based treatment and reduces unnecessary institutionalization. These young people are too often placed in out-of-state treatment facilities, hours away from their families and communities. Further segregating these children from their families and communities can impede effective treatment.

Emerging evidence shows that a major Federal program to establish comprehensive, community-based systems of care for children with serious emotional disturbances has successfully reduced costly out-of-state placements and generated positive clinical and functional outcomes. Clinically, youth in systems of care sites showed an increase in behavioral and emotional strengths and a reduction in mental health problems. For these children, residential stability improved, school attendance and school performance improved, law enforcement contacts were reduced, and substance use decreased.[52]

Consumers Need Employment and Income Supports

The low rate of employment for adults with mental illnesses is alarming. People with mental illnesses have one of the lowest rates of employment of any group with disabilities — only about 1 in 3 is employed.[53] The loss of productivity and human potential is costly to society and tragically unnecessary. High unemployment occurs despite surveys that show the majority of adults with serious mental illnesses want to work — and that many *could* work with help.[54, 55]

Many individuals with serious mental illnesses qualify for and receive either SSI or SSDI benefits. SSI is a means-tested, income-assistance program; SSDI is a social insurance program with benefits based on past earnings. A sizable proportion of adults with mental illnesses who receive either form of income support live at, or below, the poverty level. For more than a decade, the number of SSI and SSDI beneficiaries with psychiatric disabilities has increased at rates higher than each program's overall growth rate. Individuals with serious mental illnesses represent the single largest diagnostic group (35%) on the SSI rolls, while representing over a quarter (28%) of all SSDI recipients.[49, 51]

People with mental illnesses have one of the lowest levels of employment of any group with disabilities – only about 1 in 3 is employed.

Though living in poverty, SSI recipients paradoxically find that returning to work makes them even poorer, primarily because employment results in losing Medicaid coverage, which is vital in covering the cost of medications and other

treatments. According to a large, eight-State study, only 8% of those returning to full time jobs had mental health coverage.[56]

Recent Federal legislation has tried to address the loss of Medicaid and other disincentives to employment. For instance, the "Medicaid Buy-In" legislation allows States to extend Medicaid to disabled individuals who exit the SSI/SSDI rolls to resume employment, but many States cannot afford to implement Medicaid Buy-In. The Balanced Budget Act of 1997 allows States to extend Medicaid coverage to disabled individuals whose earned income is low, but still above the Federal Poverty Guidelines.

Another statutory reform — The Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999 — is problematic because its rules do not give vocational rehabilitation providers enough incentives to take on clients who have serious mental illnesses. Rather, these programs are more inclined to serve the least disabled — a process called *creaming*, in reference to the legislation's unintentional incentives for vocational rehabilitation providers to serve less disabled people rather than more disabled ones (the latter most commonly people with serious mental illnesses). One large study found that only 23% of people with schizophrenia received any kind of vocational services.[6] Since TWWIIA rewards only those providers who help their clients earn enough to no longer qualify for SSI, the bottom line is that most people with serious mental illnesses do not receive any vocational rehabilitation services at all.

Because they cannot work in the current climate, many consumers with serious mental illnesses continue to rely on Federal assistance payments in order to have health care coverage, even when they have a strong desire to be employed. Regrettably, a financial disincentive to achieve full employment exists because consumers lose Federal benefits if they become employed. Adding to the problem is the fact that most jobs open to these individuals have no mental health care coverage, so consumers must choose between employment and coverage. Consequently, they depend on a combination of disability income and Medicaid (or Medicare), all the while preferring work and independence.

For youth with serious emotional disturbances, the employment outlook is also bleak. A national study found that only 18% of these youth were employed full time, while another 21% worked part-time for one to two years after they left high school. This group had work experiences characterized by greater instability than all other disability groups.[57]

Other financial disincentives to employment exist as well, including potential loss of housing and transportation subsidies.

Over the next ten years, the U.S. economy is projected to grow by 22 million jobs, many in occupations that require on-the-job training.[58] With appropriate forms of support, people with mental illnesses could actively contribute to that economic growth, as well as to their own independence. They could fully participate in their communities. Instead, they are trapped into long-term dependence on disability income supports that leave them living below the poverty level.

A Shortage of Affordable Housing Exists

The lack of decent, safe, affordable, and integrated housing is one of the most significant barriers to full participation in community life for people with serious mental illnesses. Today, millions of people with serious mental illnesses lack housing that meets their needs.

The shortage of affordable housing and accompanying support services causes people with serious mental illnesses to cycle among jails, institutions, shelters, and the streets; to remain unnecessarily in institutions; or to live in seriously substandard housing.[59] People with serious mental illnesses also represent a large percentage of those who are repeatedly homeless or who are homeless for long periods of time.[60]

In fact, people with serious mental illnesses are over-represented among the homeless, especially among the chronically homeless. Of the more than two million adults in the U.S. who have at least one episode of homelessness in a given year, 46% report having had a mental health problem within the previous year, either by itself or in combination with

substance abuse.[59] Chronically homeless people with mental illnesses are likely to:

- Have acute and chronic physical health problems;
- Use alcohol and drugs;
- Have escalating, ongoing psychiatric symptoms; and
- Become victimized and incarcerated.[61]

A recent study shows that people who rely solely on SSI benefits — as many people with serious mental illnesses do — have incomes equal to only 18% of the median income and cannot afford decent housing in any of the 2,703 housing market areas defined by the U.S. Department of Housing and Urban Development (HUD).[62] HUD reports to Congress show that as many as 1.4 million adults with disabilities who receive SSI benefits — including many with serious mental illnesses — pay more than 50% of their income for housing.[63]

Affordable housing programs are extremely complex, highly competitive, and difficult to access. Federal public housing policies can make it difficult for people with poor tenant histories, substance use disorder problems, and criminal records — all problems common to many people with serious mental illnesses — to qualify for Section 8 vouchers and public housing units. Those who do receive Section 8 housing vouchers often cannot use them because:

- The cost of available rental units may exceed voucher program guidelines, particularly in tight housing markets;
- Available rental units do not meet Federal Housing Quality Standards for the voucher program;
- Private landlords often refuse to accept vouchers; and
- Housing search assistance is often unavailable to consumers.

The lack of decent, safe, affordable, and integrated housing is one of the most significant barriers to full participation in community life for people with serious mental illnesses.

Tragically, many housing providers discriminate against people with mental illnesses. Too many communities are unwilling to have supportive housing programs in their neighborhoods. Since the 1980s, the Federal government has had the legal tools to address these problems, yet has failed to use them effectively. Between 1989 and 2000, HUD's fair housing enforcement activities diminished, despite growing demand. The average age of complaints at their closure in FY 2000 was nearly five times the 100-day period that Congress set as a benchmark.[64]

Just as the U.S. Supreme Court's *Olmstead* decision has increased the demand for integrated and affordable housing for people with serious mental illnesses, public housing is less available. Since 1992, approximately 75,000 units of HUD public housing have been converted to "elderly only" housing and more units are being converted every year, leaving fewer units for people with disabilities.[65]

Too few mental health systems dedicate resources to ensuring that people with mental illnesses have adequate housing with supports. These systems often lack staff who are knowledgeable about public housing programs and issues. Partnerships and collaborations between public housing authorities and mental health systems are far too rare. Highly categorical Federal funding streams (*silos*) for mental health, housing, substance abuse, and other health and social welfare programs greatly contribute to the fragmentation and failure to comprehensively address the multiple service needs of many people with serious mental illnesses.

Limited Mental Health Services Are Available in Correctional Facilities

In the U.S., approximately 1.3 million people are in State and Federal prisons, and 4.6 million are under correctional supervision in the community.[66, 67] Remarkably, approximately 13 million people are jailed every year, with about 631,000 inmates serving in jail at one time. The rate of serious mental illnesses for this population is about three to four times that of the general U.S. population.[68] This means that about 7% of all incarcerated people have a current serious mental illness; the proportion with a less serious form of mental illness is substantially higher.[68]

People with serious mental illnesses who come into contact with the criminal justice system are often:

- Poor,
- Uninsured,
- Disproportionately members of minority groups,
- Homeless, and
- Living with co-occurring substance abuse and mental disorders.

They are likely to continually recycle through the mental health, substance abuse, and criminal justice systems.[69]

As a shrinking public health care system limits access to services, many poor and racial or ethnic minority youth with serious emotional disorders fall through the cracks into the juvenile justice system.

When they are put in jail, people with mental illnesses frequently do not receive appropriate mental health services. Many lose their eligibility for income supports and health insurance benefits that they need to re-enter and re-integrate into the community after they are discharged.

Women are a dramatically growing presence in all parts of the criminal justice system. Current statistics reveal that women comprise 11% of the total jail population,[70] 6% of prison inmates,[71] 22% of adult probationers, and 12% of parolees.[72] Many women entering jails have been victims of violence and present multiple problems in addition to mental and substance abuse disorders, including child-rearing and parenting difficulties, health problems, histories of violence, sexual abuse, and trauma.[73] Gender-specific services and gender-responsive programs are in increasing demand but are rarely present in correctional facilities designed for men. Early needs assessment, screening for mental and substance abuse disorders, and identification of other needs relating to self or family are critical to effectively plan treatment for incarcerated women.

More than 106,000 teens are in custody in juvenile justice facilities.[74] As a shrinking public health care system limits access to services, many poor and racial or ethnic minority youth with serious emotional disorders fall through the cracks into the juvenile justice system. (*See Goal 4 for a broader discussion of mental health screening.*)

Recent research shows a high prevalence of mental disorders in children within the juvenile justice system. A large-scale, four-year, Chicago–based study found that 66% of boys and nearly 75% of girls in juvenile detention have at least one psychiatric disorder. About 50% of these youth abused or were addicted to drugs and more than 40% had either oppositional defiant or conduct disorders.

The study also found high rates of depression and dysthymia: 17% of boys; 26% of detained girls.[75] As youth progressed further into the formal juvenile justice system, rates of mental disorder also increased: 46% of youth on probation met criteria for a serious emotional disorder compared to 67% of youth in a correctional setting.[76] Appropriate treatment and diversion should be provided in juvenile justice settings followed by routine and periodic screening.

Fragmentation Is a Serious Problem at the State Level

State mental health authorities have enormous responsibility to deliver mental health care and support services, yet they have limited influence over many of the programs consumers and families need. Most resources for people with serious mental illnesses (e.g., Medicaid) are not typically within the direct control or accountability of the administrator of the State mental health system. For example, depending on the State and how the budget is prepared, Medicaid may be administered by a separate agency with limited mental health expertise. Separate entities also administer criminal justice, housing, and education programs, contributing to fragmented services.

A Comprehensive State Mental Health Plan would create a new partnership among the Federal, State, and local governments and must include consumers and families.

The development of a Comprehensive State Mental Health Plan would create a new partnership among the Federal, State, and local governments and must include consumers and families. To be effective, the plan must reach beyond the traditional State mental health agency and the block grant to address the full range of treatment and support service programs that mental health consumers and their families should have. The planning process should support a respectful, collaborative dialogue among stakeholders, resulting in an extensive, coordinated State system of services and supports.

As States accept increased responsibility for coordinating mental health care, they should have greater flexibility in spending Federal resources to meet these needs. Using a performance partnership model, the Federal government and the State will negotiate an agreement on outcomes. This shift will then give States the flexibility to determine how they will achieve the desired outcomes outlined in their plans.

Aligning relevant Federal programs to support Comprehensive State Mental Health Plans can have the powerful impact of fostering consumers' independence and their ability to live, work, learn, and participate fully in their communities. (*See Recommendations 2.3 and 2.4.*)

Consumers and Families Need Community-based Care

In the 1999 *Olmstead v. L.C.* decision, the U.S. Supreme Court held that the unnecessary institutionalization of people with disabilities is discrimination under the Americans with Disabilities Act.[77] The Court found that:

> "...confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

President Bush urged promptly implementing the *Olmstead* decision in his 2001 Executive Order 13217, mobilizing Federal resources in support of *Olmstead.* However, many adults and children remain in institutions instead of in more appropriate community-based settings.

On a separate topic, the General Accounting Office (GAO) recently issued a report that illustrates the tragic and unacceptable circumstances that result in thousands of parents being forced to place their children into the child welfare or juvenile justice systems each year so that they may obtain the mental health services they need. Loving and responsible parents who have exhausted their savings and health insurance face the wrenching decision of surrendering their parental rights and tearing apart their families to secure mental health treatment for their troubled children. The GAO report estimates that, in 2001, parents were forced to place more than 12,700 children in the child welfare or juvenile justice systems as the last resort for those children to receive needed mental health care treatment. Moreover, these numbers are actually an undercount because 32 states, including the five

largest, were unable to provide data on the number of children affected.[78]

According to the report, several factors contribute to the consequence of "trading custody for services," including:

- Limitations of both public and private health insurance,
- Inadequate supply of mental health services,
- Limited availability of services through mental health agencies and schools, and
- Difficulties meeting eligibility rules for services.

When parents cede their rights in order to place their children in foster care or in a program for delinquent youth, they may also be inadvertently placing their children at risk for abuse or neglect.[79] These placements also increase the financial burden on State child welfare and juvenile justice authorities. A more family-friendly policy must be found to remedy this situation.

Consumers Face Difficulty in Finding Quality Employment

Only about one-third of people with mental illnesses are employed, and many of them are under-employed.[53] For example, about 70% of people with serious mental illnesses with college degrees earned less than $10 per hour.[80] Overall, people with psychiatric disabilities earned a median wage of only about $6 per hour versus $9 per hour for the general population.[53]

Problems begin long before consumers enter the work force. Many individuals with serious mental illnesses lack the necessary high school and post-secondary education or training vital to building careers. A major study found that youth with emotional disturbances have the highest percentage of high school non-completion and failing grades compared with other disabled groups.[81]

Only about one-third of people with mental illnesses are employed, and many of them are under-employed.

Special education legislation — the Individuals with Disabilities Education (IDEA) Act — was designed to prepare school-aged youth to make the transition to the workplace, but its promise remains largely unfulfilled. Similarly, the Americans with Disabilities Act (ADA) has not fulfilled its potential to prevent discrimination in the workplace. Workplace discrimination, either overt or covert, continues to occur. According to surveys conducted over the past five decades, employers have expressed more negative attitudes about hiring workers with psychiatric disabilities than any other group.[82; 83] Economists have found unexplained wage gaps that are evidence of discrimination against those with psychiatric disabilities.[84]

The Use of Seclusion and Restraint Creates Risks

An emerging consensus asserts that the use of seclusion and restraint in mental health treatment settings creates significant risks for adults and children with psychiatric disabilities. These risks include serious injury or death, re-traumatizing people who have a history of trauma, loss of dignity, and other psychological harm. Consequently, it is inappropriate to use seclusion and restraint for the purposes of discipline, coercion, or staff convenience.

Seclusion and restraint are safety interventions of last resort; they are not treatment interventions. In light of the potentially serious consequences, seclusion and restraint should be used only when an imminent risk of danger to the individual or others exists and no other safe, effective intervention is possible. It is also inappropriate to use these methods instead of providing adequate levels of staff or active treatment.

Achieving the Goal

RECOMMENDATION **2.1 Develop an individualized plan of care for every adult with a serious mental illness and child with a serious emotional disturbance.**

Develop Individualized Plans of Care for Consumers and Families

The Commission recommends that each adult with a serious mental illness and each child with a serious emotional disturbance have an individualized plan of care. These plans of care give consumers, families of children with serious emotional disturbances, clinicians, and other providers a genuine opportunity to construct and maintain meaningful, productive, and healing partnerships. The goals of these partnerships include:

- Improving service coordination,
- Making informed choices that will lead to improved individual outcomes, and
- Ultimately achieving and sustaining recovery.

The plans should form the basis for care that is both consumer centered and coordinated across different programs and agencies. A consumer's plan of care should describe the services and supports they need to achieve recovery. The funding for the plan would then follow the consumer, based on their individualized care plan. For those consumers who need multiple services and supports, the burden of coordination and access to care should not rest solely on them or on their families, but rather it should be shared with service providers.

Providers should develop these customized plans in full partnership with consumers.

Consumer needs and preferences should drive the type and mix of services provided, and should take into account the developmental, gender, linguistic, or cultural aspects of providing and receiving services. Providers should develop these customized plans in full partnership with consumers, while understanding changes in individual needs across the lifespan and the obligation to review treatment plans regularly. For consumers and families, the system should be easy to understand and navigate. The Commission recommends that SAMHSA convene a consensus panel to examine and explore developing models to guide individual plans of care.

Where a range of services are available, increased opportunities for choice will create a more viable marketplace for mental health care and provide a greater level of satisfaction by giving consumers and families control over important funding decisions that affect their lives. A recent Medicaid Cash and Counseling Demonstration waiver program that focuses on people with physical disabilities, developmental disabilities/mental retardation, and older adults confirms what many have long suspected. The evaluation, jointly funded by HHS and the Robert Wood Johnson Foundation, found that, when compared to traditional agency-directed personal care services, consumer-directed services resulted in:

- Higher client satisfaction,
- Increased numbers of needs being met, and
- Equivalent levels of health and safety in a large population of people with disabilities.[85]

In this demonstration, these selected Medicaid waiver program beneficiaries choose their own support services (e.g., personal care attendants and adaptive equipment) from an approved list. The Commission sees the value in undertaking a similar demonstration waiver program to evaluate the potential benefits for people with mental illnesses.

An exemplary program that expressly targets children with serious emotional disturbances and their families, Wraparound Milwaukee strives to

integrate services and funding for the most seriously affected children and adolescents. (*See Figure 2.1.*) Most program participants are racial or ethnic minority youth in the child welfare and juvenile justice systems. Wraparound Milwaukee demonstrates that the seemingly impossible can be made possible: children's care can be seamlessly integrated. The services provided to children not only produce better clinical results, reduce delinquency, and result in fewer hospitalizations, but are cost-effective.[86]

Each consumer or child's family should receive the technical assistance necessary to develop the individual plan of care, including:

- Necessary information about services and supports,
- Opportunities to network with other consumers and families, and
- Participation in a full partnership with providers on decisions about treatment and services.

Youth with serious emotional disturbances should participate in meetings to ensure that their voices are heard in educational decisions that affect their school-based intervention and placement, particularly in the student's Individualized Education Program (IEP). To succeed, the plan must also be supported by the proposed Comprehensive State Mental Health Plan. *(See Recommendation 2.4.)*

FIGURE 2.1. MODEL PROGRAM: Integrated System of Care for Children with Serious Emotional Disturbances and Their Families

Program	Wraparound Milwaukee
Goal	To offer cost-effective, comprehensive, and individualized care to children with serious emotional disturbances and their families. The children and adolescents that the program serves are under court order in the child welfare or juvenile justice system; 64% are African American.
Features	Provides coordinated system of care through a single public agency (Wraparound Milwaukee) that coordinates a crisis team, provider network, family advocacy, and access to 80 different services. The program's $30 million budget is funded by pooling child welfare and juvenile justice funds (previously spent on institutional care) and by a set monthly fee for each Medicaid-eligible child. (The fee is derived from historical Medicaid costs for psychiatric hospitalization or related services.)
Outcomes	Reduced juvenile delinquency, higher school attendance, better clinical outcomes, lower use of hospitalization, and reduced costs of care. Program costs $4,350 instead of $7,000 per month per child for residential treatment or juvenile detention.[86]
Biggest challenge	To expand the program to children with somewhat less severe needs who are at risk for worse problems if they are unrecognized and untreated.
How other organizations can adopt	Encourage integrated care and more individualized services by ensuring that funding streams can support a single family-centered treatment plan for children whose care is financed from multiple sources.
Sites	Milwaukee and Madison, Wisconsin; Indianapolis, Indiana; and the State of New Jersey

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RECOMMENDATION **2.2 Involve consumers and families fully in orienting the mental health system toward recovery.**

Involve Consumers and Families in Planning, Evaluation, and Services

Through consumer and family member public testimony, comments, and letters, the Commission is convinced of the need to increase opportunities for consumers and family members to share their knowledge, skills, and experiences of recovery. Recovery-oriented services and supports are often successfully provided by consumers through consumer-run organizations and by consumers who work as providers in a variety of settings, such as peer-support and psychosocial rehabilitation programs.

Consumers who work as providers help expand the range and availability of services and supports that professionals offer. Studies show that consumer-run services and consumer-providers can broaden access to peer support, engage more individuals in traditional mental health services, and serve as a resource in the recovery of people with a psychiatric diagnosis.[18] Because of their experiences, consumer-providers bring different attitudes, motivations, insights, and behavioral qualities to the treatment encounter.[87; 88]

In the past decade, mental health consumers have become involved in planning and evaluating the quality of mental health care and in conducting sophisticated research to affect system reform. Consumers have created and operated satisfaction assessment teams, used concept-mapping technologies, and carried out research on self-help, recovery, and empowerment.[89; 90]

Local, State, and Federal authorities must encourage consumers and families to participate in planning and evaluating treatment and support services. The direct participation of consumers and families in developing a range of community-based, recovery-oriented treatment and support services is a priority.

Consumers and families with children with serious emotional disturbances have a key role in expanding the mental health care delivery workforce and creating a system that focuses on recovery. Consequently, consumers should be involved in a variety of appropriate service and support settings. In particular, consumer-operated services for which an evidence base is emerging should be promoted.

RECOMMENDATION **2.3 Align relevant Federal programs to improve access and accountability for mental health services.**

Realign Programs to Meet the Needs of Consumers and Families

The Federal government is the largest single payer for mental health and supportive services, including health care, employment, housing, and education. To be effective, Federal funding and regulatory systems must make the necessary range of services, treatments, and supports accessible.

The Commission has come to the emphatic conclusion that transforming mental health care in America requires at least two fundamental undertakings:

- Relevant Federal programs that determine eligibility, policy, and financing in the core areas of health care, housing, employment, education, and child welfare must examine their potential to better align their programs to meet the needs of adults and children with mental illnesses. Because of the exceedingly

high rates of mental illnesses among incarcerated populations, this examination must also include Federal policy, program, and financing roles in the criminal and juvenile justice systems.

- The President's vision is to ensure that all Americans with disabilities have opportunities to live, work, learn, and participate fully in the community. Federal agencies can greatly help to realize this vision by better aligning their programs that address the systems mentioned above. The Commission believes that realigning Federal programs will help provide States with incentives to develop and use Comprehensive State Mental Health Plans. (*See Recommendation 2.4.*)

Federal expenditures and policies have a tremendous impact on consumers and families. Particularly at the Federal level, leadership must increase opportunities for consumers and families, and develop innovative solutions.

The Federal government must also provide leadership in demonstrating accountability for funding approaches and in removing regulatory and policy barriers. The funding and regulatory systems should advance the goal of making the mental health system consumer- and family-driven and should encourage choice and self-determination.

In a transformed system, the key goals of a revised Federal agenda for mental health would include:

- Clarifying and coordinating regulations and funding guidelines that are relevant to people with mental illnesses for housing, vocational rehabilitation, criminal and juvenile justice, social security, and education to improve access and accountability for effective services; and
- Providing guidance to States to create a Comprehensive State Mental Health Plan that would address the same fragmentation and coordination issues at the State level. (*See Recommendation 2.4.*)

As States increase their levels of interagency coordination, the Federal agencies would provide greater flexibility in how funds could be used.

The Commission recommends that HHS take the lead responsibility to develop a cross-Department mental health agenda with the goal of better aligning Federal policy on mental health treatment and support services across agencies and reducing fragmentation in services. The HHS Secretary should require that key agencies and programs that serve people with serious mental illnesses coordinate their responsibilities, including:

- Substance Abuse and Mental Health Services Administration (SAMHSA),
- National Institutes of Health (NIH),
- Centers for Medicare and Medicaid Services (CMS),
- Administration for Children and Families (ACF),
- Social Security Administration (SSA),
- U.S. Department of Veterans Affairs (VA),
- U.S. Department of Education (ED),
- The juvenile and adult criminal justice systems,
- Child welfare,
- Vocational rehabilitation, and
- Housing.

Align Federal Financing for Health Care

The two largest Federal health care programs — Medicare and Medicaid — strongly influence the nature and characteristics of the health care reimbursement system. How States use Medicaid to finance mental health care varies greatly. All too often, the interplay of existing policies, waivers, and exemptions can cause the collaboration between the State mental health authorities and State Medicaid programs directors to be inconsistent.

Beneficiaries must be able to exercise choice, self-direction, and control over their health care services. To provide this choice, critical issues must be addressed so that Federal funding programs and State resources are coordinated. In transforming the health care financing system, the various characteristics and unique local needs must be addressed.

Both CMS and SSA recognize the challenges to modernizing the current delivery system for people with disabilities, as well as the fiscal constraints under which States operate. New ways of doing business, innovation, and a willingness to explore viable options will lead the way to improving the system.

The Balanced Budget Act of 1997 allows States to extend Medicaid coverage to individuals with disabilities whose earned income is low, but still above the Federal Poverty Guidelines by up to 250%. This action directly benefits individuals with disabilities who could not ordinarily qualify for Medicaid. By setting the net income eligibility at this level, States can provide Medicaid coverage to more individuals with disabilities who might not be able to be employed.

The Commission recognizes that Medicaid demonstration projects are an essential tool to inform policy makers and Federal payers about the effectiveness and fiscal impact of health care innovations. Therefore, the Commission recommends introducing legislation to implement those New Freedom Initiative Demonstration proposals included in the President's Fiscal Year 2004 Budget.

Specifically, these demonstrations include:

- "Money Follows the Individual" Rebalancing,
- Community-based alternatives for children who are currently residing in psychiatric residential treatment facilities, and
- Respite care services for caregivers of adults with disabilities or long-term illnesses, and respite care for caregivers of children with substantial disabilities.

DEMONSTRATION: "Money Follows the Individual" Rebalancing

This demonstration creates a system of flexible financing for long-term services and supports that enables available funds to move with the individual to the most appropriate and preferred setting as the individual's needs and preferences change. To the participant, the movement of funds is seamless.

This project would help States develop and adopt a coherent strategy to make their long-term care systems more responsive to the needs and desires of its citizens, more cost-effective, less dependent on institutional settings, and more responsive to the ADA. This demonstration would also support State initiatives to increase self-direction and comply with the *Olmstead* decision.

> ***Rebalancing*** means adjusting a State's Medicaid programs and services to achieve a more equitable balance between the proportion of total Medicaid long-term support expenditures used for institutional services (i.e., nursing facilities and intermediate care facilities - mental retardation) and the proportion of funds used for community-based support under its State Plan and waiver services. A balanced, long-term support system offers individuals a reasonable array of options, including meaningful community and institutional choices.

DEMONSTRATION: Community-based Alternatives for Children in Psychiatric Residential Treatment Facilities

Over the last decade, psychiatric residential treatment facilities have become the primary provider for children with serious emotional disturbances who require an institutional level of care. The Medicaid program provides Federal matching funds for inpatient psychiatric services for children under age 21 in hospitals or in psychiatric residential treatment facilities. A primary tool for States to develop community-based alternatives to institutional settings, such as hospitals, is the Home and Community-based Services waiver authority under Section 1915(c) of the Social Security Act.

However, since psychiatric residential treatment facilities are not explicitly listed as an institution in the Act, this tool is not available to States.

Extending home- and community-based services (HCBS) as an alternative to residential treatment facilities could allow children to receive treatment in their own homes, surrounded by their families, at a cost per child that would be less than the cost of institutional care. However, no analysis of the effectiveness or efficiency of such an approach exists. While limiting Federal financial exposure by capping total participation, a demonstration would allow CMS to develop reliable cost and utilization data to evaluate the impact of Medicaid waiver services on the effectiveness of community placements for children with serious emotional disturbances. The data would also serve as a useful predictor of what would be expected if permanent authority is granted for the HCBS waiver as an alternative to psychiatric residential treatment centers.

DEMONSTRATION: Respite Care Services for Caregivers

When the demands of caregiving overwhelm caregivers, people with disabilities may be forced to leave their homes for a less desirable, more restrictive environment. Fortunately, respite services that provide temporary relief for caregivers can enable individuals with disabilities to remain in their homes and communities.

Although respite care can take many forms, its essential purpose is to provide community-based, planned or emergency short-term relief to family caregivers, alleviating the pressures of ongoing care. It is frequently provided in the family home. Without respite care, family caregivers who are forced to stay at home to provide care experience significant stress, loss of employment, financial burdens, and marital difficulties. Many caregivers report that it is unsafe to leave their family members at home alone; they are unable to leave their family members with another relative; and they face barriers in accessing generic day care or companion services. A demonstration would expand the ability of States to develop respite care service alternatives outside the scope of an HCBS waiver and test the financial impact of this service.

The Commission also recommends that CMS work with relevant HHS components and other Federal agencies to explore and propose demonstrations for future fiscal years to address the following areas:

- The Institutions for Mental Diseases (IMDs) exclusion be addressed within Medicaid reform efforts, including issues such as Home and Community-based Services Demonstration as an alternative to IMDs or a redefinition of IMDs and the services funded, and
- Self-directed services and supports for people with mental illnesses.

Make Supported Employment Services Widely Available

Every adult served in the mental health system and every young person with serious emotional disturbances making the transition from school to work must have access to supported employment services if they are to participate fully in society.

> Most vocational rehabilitation services are ineffective for the small proportion of people with mental illnesses who manage to get them.

Disturbingly, most vocational rehabilitation services are ineffective for the small proportion of people with mental illnesses who manage to get them. Traditional vocational services that most vocational rehabilitation programs offer are far less effective for people with serious mental illnesses than a widely researched approach known as *supported employment*. Supported employment programs assign an employment specialist to the treatment team. That specialist helps consumers by conducting assessments and rapid job searches, and by providing ongoing, on-the-job support. Studies of supported employment show that 60% to 80% of people with serious mentally illnesses obtain at least one competitive job (compared to 19% who remained in traditional vocational programs) — a clear success rate.[54] The cost of supported employment is similar to that of traditional vocational services. (*See Figure 2.2.*)

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FIGURE 2.2. MODEL PROGRAM: Supported Employment for People with Serious Mental Illnesses

Goal	To secure employment quickly and efficiently for people with mental illnesses. Alarmingly, only about one-third of people with mental illnesses are employed,[53] yet most wish to work.
Features	An employment specialist on a mental health treatment team. The employment specialist collaborates with clinicians to make sure that employment is part of the treatment plan. Then the specialist conducts assessments and rapid job searches and provides ongoing support while the consumer is on the job.
Outcomes	In general, about 60% to 80% of those served by the supported employment model obtain at least one competitive job, according to findings from three randomized controlled trials in New Hampshire; Washington, DC; and Baltimore.[55] Those trials find the supported employment model far superior to traditional programs that include prevocational training. The cost of the supported employment model is no greater than that for traditional programs, suggesting that supported employment is cost-effective.
Biggest challenge	To move away from traditional partial hospital programs, which are ineffective at achieving employment outcomes but are still reimbursable under Medicaid.
How other organizations can adopt	Restructure State and Federal programs to pay for evidence-based practices, such as Individual Placement and Support (IPS)[55] that help consumers achieve employment goals rather than pay for ineffective, traditional day treatment programs that do not support employment.
Sites	30 States in the United States, Canada, Hong Kong, Australia, and 6 European countries

Even though supported employment is effective, few people with mental illnesses receive these services. One reason is that individuals with psychiatric disabilities often receive services that may be called "supported employment," but are supported employment in name only. These vocational services lack the key ingredients that make supportive employment effective. Additionally, State-Federal vocational rehabilitation services are funded for limited time periods and do not pay for ongoing job support (other than a "post-employment services" status that is rarely used). Similarly, Medicaid does not reimburse for most vocational rehabilitation services. Thus, the lack of available financing mechanisms and the inadequately implemented supported employment models are barriers that prevent people with mental illnesses from benefiting from supported employment.

Studies of supported employment show that 60% to 80% of people with serious mentally illnesses obtain at least one competitive job — a clear success rate.

The Commission recommends strengthening and expanding supported employment services, such as Individualized Placement and Support,[55] to all people with psychiatric disabilities. The system must make opportunities for supported employment available for anyone who wants to participate. To make supported employment services more widely available, the Commission urges CMS to provide technical assistance to States on how to effectively use the Medicaid

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Rehabilitation Services Option to fund those components of supported employment that are consistent with Medicaid policy. The Commission encourages the Social Security Administration to evaluate the possibility of removing disincentives to employment in both the SSI and SSDI programs.

The Commission encourages States to use Medicaid Buy-In legislation to extend Medicaid coverage to disabled individuals who are working.

The widespread use of supported employment, coupled with the reduced disincentive to employment, could result in productive work and independence for consumers while accruing enormous cost-savings in Federal disability payments. Additionally, CMS and SSA should determine the feasibility of using savings accrued by SSA as beneficiaries go back to work to offset increased State and Federal Medicaid costs.

CMS and SSA should launch a national campaign to encourage States to use this powerful incentive to employment. The campaign should be designed to:

- Reduce barriers to implementation;
- Improve SSA and CMS communication; and
- Promote education and outreach to consumers, youth, families, vocational rehabilitation counselors, and community rehabilitation programs.

The Commission recommends developing a Federal-State interagency initiative involving all Federal agencies that are charged with addressing mental health, employment, and disability issues. Through this initiative, agencies can:

- Collaborate to inventory and assess existing Federal programs,
- Better coordinate the administration of these programs, and
- Promote interagency demonstration projects that are designed to eliminate employment barriers and increase employment opportunities for youth and adults with mental illnesses.

Make Housing with Supports Widely Available

The Commission believes it is essential to address the serious housing affordability problems of people with severe mental illnesses who have extremely low incomes. Progress toward this objective will significantly advance the goal of ending chronic homelessness and will have a great impact on the crisis of inadequate housing and homelessness for people with severe mental illnesses.

Research shows that consumers are much more responsive to accepting treatment after they have housing in place.[91] People with mental illnesses consistently report that they prefer an approach that focuses on providing housing for consumers or families first. However, affordable housing alone is insufficient. Flexible, mobile, individualized support services are also necessary to support and sustain consumers in their housing. Many consumers have troubled tenant histories and higher rates of incarceration — both of which can lead to long-term ineligibility for Federal housing programs, such as Section 8 vouchers and public housing. In addition, access to ongoing support services is limited

Research shows that consumers are much more responsive to accepting treatment after they have housing in place.

Research and demonstration programs have documented the effectiveness of the supportive housing model for people with serious mental illnesses.[92; 93] Research has also found that permanent supportive housing can be cost effective when compared to the cost of homelessness.[94] For example, a University of Pennsylvania study found that homeless people with mental illnesses who were placed in permanent supportive housing cost the public $16,282 less per person per year compared to their previous costs for mental health, corrections, Medicaid, and public institutions and shelters.[92]

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The Commission recommends making affordable housing more accessible to people with serious mental illnesses and ending chronic homelessness among this population. To begin, in partnership with the Interagency Council on Homelessness (comprising 20 Federal agencies), the Department of Housing and Urban Development (HUD) should develop and implement a comprehensive plan designed to facilitate access to 150,000 units of permanent supportive housing for consumers and families who are chronically homeless. During the next ten years, this initiative should develop specific cost-effective approaches, strategies, technical assistance activities, and actions to be implemented at the Federal, State, and local levels. Expanding and ensuring a continuum of housing services would represent positive elements to include in such a plan. The Commission recommends that individuals who have a history of serious mental illnesses be given fair access to these 150,000 units of supportive housing.

The Commission recommends that States and communities commit to the goal of ending chronic homelessness and develop the means to achieve it.

The Commission recognizes that national leadership must make a concerted effort to address the problem of homelessness and lack of affordable housing among people with serious mental illnesses. The Commission urges HUD to collaborate with HHS, VA, and other relevant agencies to provide leadership to States and local communities to improve housing opportunities for this population. HUD should aggressively pursue administrative, regulatory, and statutory changes to existing mainstream housing programs; e.g., Section 811 Supportive Housing. Input from stakeholders to identify existing barriers to accessing housing should be an integral part of HUD's considerations.

Address Mental Health Problems in the Criminal Justice and Juvenile Justice Systems

Providing adequate services in correctional facilities for people with serious mental illnesses who do need to be there is both prudent and required by law. The Eighth Amendment of the U.S. Constitution protects the right to treatment for acute medical problems, including psychiatric problems, for inmates and detainees in America's prisons and jails. Professional organizations have published guidelines for mental health care in correctional settings and some States have implemented them.[69; 95-97]

All too often, people are misdiagnosed or not diagnosed with the root problem of mental illnesses. It is important to keep adults and youth with serious mental illnesses who are not criminals out of the criminal justice system. Too often, the criminal justice system unnecessarily becomes a primary source for mental health care. The potential for recovery for the offender with a mental illness is too frequently derailed by inadequate care and the superimposed stigma of a criminal record. Cost studies suggest that taxpayers can save money by placing people into mental health and substance abuse treatment programs instead of in jails and prisons.[98; 99] With the appropriate diversion and re-entry programs, these consumers could be successfully living in and contributing to their communities. Many non-violent offenders with mental illnesses could be diverted to more appropriate and typically less expensive supervised community care. Proven models exist for diversion programs operating in many areas around the country.

Too often, the criminal justice system unnecessarily becomes a primary source for mental health care.

Unfortunately, one of the groups most isolated from society are those consumers who attempt to return to the community after being incarcerated. Linking people with serious mental illnesses to community-based services — and in the case of youth, also to educational services — when they are diverted or released from jails or prisons through re-entry transition programs is an important strategy to re-integrate consumers into their communities.

The Commission recommends widely adopting adult criminal justice and juvenile justice diversion and re-entry strategies to avoid the unnecessary criminalization and extended incarceration of non-violent adult and juvenile offenders with mental

illnesses. HHS and the Department of Justice, in consultation with the Department of Education, should provide Federal leadership to help States and local communities develop, implement, and monitor a range of adult and youth diversion and re-entry strategies.

RECOMMENDATION 2.4 Create a Comprehensive State Mental Health Plan.

Create Comprehensive State Mental Health Plans to Coordinate Services

The Commission envisions that developing and using Comprehensive State Mental Health Plans will greatly facilitate new partnerships among the Federal, State, and local governments to better use existing resources for people with mental illnesses. Incorporating the principles in this report, at the very least, the plan should:

- Increase the flexibility of resource use at the State and local levels, encouraging innovative uses of Federal funding and flexibility in setting eligibility requirements;
- Have State and local levels of government be more accountable for results, not solely to Federal funding agencies, but to consumers and families as well; and
- Expand the options and the array of services and supports.

To accomplish this change, the Federal government must reassess pertinent financing and eligibility policies and align reporting requirements to avoid duplication, promote consistency, and seek accountability from the States.

The underlying premise of the Commission's support for Comprehensive State Mental Health Plans is consistent with the principles of Federalism — providing incentives to States by granting increased flexibility in exchange for greater accountability and improved outcomes. For example, California's AB-34 program, designed to meet the needs of adults with mental illnesses who are homeless, demonstrates that services provided through programs that allow flexibility in financing care do, indeed, produce positive outcomes that benefit individuals, families, and society while most efficiently using resources. (*See Figure 2.3.*)

The intended outcome of Comprehensive State Mental Health Plans is to encourage States and localities to develop a comprehensive strategy to respond to the needs and preferences of consumers or families.

The Commission recommends that each State, Territory, and the District of Columbia develop a Comprehensive State Mental Health Plan. The plans will have a powerful impact on overcoming the problems of fragmentation in the system and will provide important opportunities for States to leverage resources across multiple agencies that administer both State and Federal dollars. The Office of the Governor should coordinate each plan. The planning process should support a dialogue among all stakeholders and reach beyond the traditional State mental health agency to address the full range of treatment and support service programs that consumers and families need. The final result should be an extensive and coordinated State system of services and supports that work to foster consumer independence and their ability to live, work, learn, and participate fully in their communities.

FIGURE 2.3. MODEL PROGRAM: Integrated Services for Homeless Adults with Serious Mental Illnesses	
Program	AB-34 Projects – Named after California Legislation of 2000
Goal	To "do whatever it takes" to meet the needs of homeless persons with serious mental illnesses, whether on the street, under a bridge, or in jail.
Features	Outreach (often by formerly homeless people), comprehensive services, 24/7 availability, partnerships with community providers, and real-time evaluation. Flexible funding, not driven by eligibility requirements.
Outcomes	66% decrease in number of days of psychiatric hospitalization, 82% decrease in days of incarceration, and 80% fewer days of homelessness.[100]
Biggest challenge	To change the culture, attitudes, and values around treating difficult populations with different strategies. Traditional services and providers tend to want to continue "business as usual" and follow funding streams rather than integrate services or share responsibility.
How other organizations can adopt	Change infrastructure to integrate services. This concept is a different way of doing business and requires links to a broader array of services, not just mental health.
Web sites	www.ab34.org (The web site is currently being developed and will be expanded soon.) www.dmh.ca.gov (click on *Community Mental Health Services, Homeless Mentally Ill Programs*, and then *Integrated Services for the Homeless Mentally Ill.*
Sites	38 California counties

RECOMMENDATION 2.5 Protect and enhance the rights of people with mental illnesses.

Protect and Enhance Consumer and Family Rights

The Commission strongly endorses protecting and enhancing the rights of people with serious mental illnesses and children with serious emotional disturbances, particularly in the following four areas:

- Fully integrating consumers into their communities under the *Olmstead* decision,
- Eliminating conditions under which parents must forfeit parental rights so that their children with serious emotional disturbances can receive adequate mental health treatment,
- Eliminating discrimination — especially in employment — based on past assignment of a psychiatric diagnosis or mental health treatment, and
- Reducing the use of seclusion and restraint in mental health treatment settings.

End Unnecessary Institutionalization

The Commission calls for swiftly eliminating unnecessary and inappropriate institutionalization that severely limits integrating adults with serious mental illnesses and children with serious emotional disturbances into their communities.

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Federal, State, and local entities must continue to implement *Olmstead* and ensure full community integration for all individuals with psychiatric disabilities. The Commission urges the HHS Office for Civil Rights (OCR) to follow through on the current *Olmstead* voluntary compliance initiatives, including widely disseminating information about *Olmstead* compliance and promoting community care, technical assistance for States, and clarifying Medicaid policies that affect individuals with serious mental illnesses.

Eliminate the Need to Trade Custody for Mental Health Care

The Commission is resolved that Federal, State, and local governments must work together with family and provider organizations to eliminate the practice of trading custody for care and to find a more family-friendly solution. One way to correct this appalling circumstance and allow children to stay with their families is to provide family-centered services.

The Commission endorses the General Accounting Office's recommendation:

> "The Departments of Health and Human Services (HHS) and Justice (DOJ) should consider the feasibility of tracking children placed by their parents in the child welfare and juvenile justice systems to obtain mental health services. HHS, DOJ, and the Department of Education (Education) should develop an interagency working group to identify the causes of the misunderstandings at the State and local levels and create an action plan to address those causes. These agencies should also continue to encourage States to evaluate the programs that the States fund or initiate and determine the most effective means of disseminating the results of these and other available studies."[101]

If States reallocated the funds that currently pay for inappropriate services toward more appropriate mental health treatment and supports, more children could remain with their families. Not only would this shift of funds and services better help the children toward their own recovery, but it would also use resources more wisely.

End Employment Discrimination

The Commission acknowledges the need to eliminate employment discrimination in any form; it is too often based on current or past psychiatric diagnosis or mental health treatment. In particular, the Commission recommends strong national leadership to end employment discrimination against people with psychiatric disabilities in the public and private sectors.

All levels of Federal, State, and local government should review their employment policies to eradicate discriminatory practices on the basis of mental health treatment or diagnosis. A great opportunity exists for all levels of government and the private sector to serve as models by hiring individuals with disabilities.

Reduce the Use of Seclusion and Restraint

The Commission notes that professionals agree that the best way to reduce restraint deaths and injuries is to minimize restraint use as much as possible. High restraint rates are seen as evidence of treatment failure.

The Commission endorses reducing the use of seclusion and restraint and, when such interventions are used, appropriately trained personnel should administer them as safely and humanely as possible. It is also important to apply preventive measures (e.g., de-escalation techniques) that will minimize the need to use seclusion and restraint.

Many facilities and State agencies have had substantial success in reducing the use of restraint, while also reducing staff and patient injuries. However, much work remains for both institutional and community settings before this cultural change can fully occur. Leadership to continue these important changes will move us closer to a transformed mental health system that is defined by respect, compassion, and collaborative partnerships with the people it serves.

The Commission recommends that States have mechanisms to:

- Report deaths and serious injuries resulting from the use of seclusion and restraint,
- Ensure that they investigate these incidents, and
- Track patterns of seclusion and restraint use.

To encourage frank and complete assessments and to ensure the individual's confidentiality, these internal reviews should be protected from disclosure.

The Commission recognizes that to decrease the use of seclusion and restraint, policies and facility guidelines must be developed collaboratively with input from consumers, families, treatment professionals, facility staff, and advocacy groups. Supporting technical assistance, staff training, and consumer/peer-delivered training and involvement should be implemented to effectively improve and implement policies and guidelines based on research about seclusion and restraint. To improve the quality of care and ensure positive outcomes, model programs and best practices must be identified and information must be shared.

GOAL 3 Disparities in Mental Health Services Are Eliminated.

RECOMMENDATIONS

3.1 Improve access to quality care that is culturally competent.

3.2 Improve access to quality care in rural and geographically remote areas.

Understanding the Goal

Minority Populations Are Underserved in the Current Mental Health System

Racial and ethnic minority Americans comprise a substantial and vibrant segment of the U.S. population, enriching our society with many unique strengths, cultural traditions, and important contributions. As a segment of the overall population, these groups are growing rapidly; current projections show that by 2025, they will account for more than 40% of all Americans.[102]

Unfortunately, the mental health system has not kept pace with the diverse needs of racial and ethnic minorities, often underserving or inappropriately serving them. Specifically, the system has neglected to incorporate respect or understanding of the histories, traditions, beliefs, languages, and value systems of culturally diverse groups. Misunderstanding and misinterpreting behaviors have led to tragic consequences, including inappropriately placing minorities in the criminal and juvenile justice systems.

While bold efforts to improve services for culturally diverse populations currently are underway, significant barriers still remain in access, quality, and outcomes of care for minorities. As a result, American Indians, Alaska Natives, African Americans, Asian Americans, Pacific Islanders, and Hispanic Americans bear a disproportionately high burden of disability from mental disorders. This higher burden does not arise from a greater prevalence or severity of illnesses in these populations. Rather it stems from receiving less care and poorer quality of care.[16]

The mental health system has not kept pace with the diverse needs of racial and ethnic minorities, often underserving or inappropriately serving them.

Receiving appropriate mental health care depends on accurate diagnosis. Racial and ethnic minorities' higher rates of misdiagnosis may contribute to their greater burden of disability. For instance, African Americans are more likely to be overdiagnosed for schizophrenia and underdiagnosed for depression.[16] To compound this problem, physicians are less likely to prescribe newer generation antidepressant or antipsychotic medications to African American consumers who need them.[103]

The report, *Mental Health: Culture, Race and Ethnicity, A Supplement to Mental Health: A Report of the Surgeon General,* highlighted

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striking disparities in mental health services for racial and ethnic minority populations. For example, these populations:

- Are less likely to have access to available mental health services,
- Are less likely to receive needed mental health care,
- Often receive poorer quality care, and
- Are significantly under-represented in mental health research.[16]

Minorities Face Barriers to Receiving Appropriate Mental Health Care

Although many barriers deter minority populations from accessing and receiving proper treatment, some barriers are shared by all populations. For instance, all populations with mental disorders are affected by fragmented services, unavailable services, and high costs, as well as societal stigma.

However, additional barriers prevent racial and ethnic minorities from seeking services, including:

- Mistrust and fear of treatment;
- Different cultural ideas about illnesses and health;
- Differences in help-seeking behaviors, language, and communication patterns;
- Racism;
- Varying rates of being uninsured; and
- Discrimination by individuals and institutions.[16]

Racial and ethnic minorities are seriously under-represented in the core mental health professions.

Cultural Issues Also Affect Service Providers

Cultural issues affect not only those who seek help but also those who provide services. Each group of providers embodies a culture of shared beliefs, norms, values, and patterns of communication. They may perceive mental health, social support, diagnosis, assessment, and intervention for disorders in ways that are both different from one another and different from the culture of the person seeking help.

While professionals of all racial and ethnic backgrounds can and do deliver culturally competent care, much of the existing workforce is inadequately trained in this area. Racial and ethnic minorities are seriously under-represented in the core mental health professions, many providers are inadequately prepared to serve culturally diverse populations, and investigators are not trained in research on minority populations.[104; 105]

Without concerted efforts to remedy this problem, the shortage of providers and researchers will intensify the disproportionate burden of mental disorders on racial and ethnic minorities. With the rapid growth in minority populations, disparities will deepen if they are not systemically and urgently addressed.

Rural America Needs Improved Access to Mental Health Services

The vast majority of all Americans living in underserved, rural, and remote areas also experience disparities in mental health services. Rural America makes up 90% of our Nation's landmass and is home to approximately 25% of the U.S. population.[102] Despite these proportions, rural issues are often misunderstood, minimized, and not considered in forming national mental health policy. Too often, policies and practices developed for metropolitan areas are erroneously assumed to apply to rural areas.

Access to mental health care, attitudes toward mental illnesses, and cultural issues that influence whether people seek and receive care differ profoundly between rural and urban areas.

While the prevalence and incidence of serious mental illnesses among adults and serious emotional disturbances for children are similar in rural and urban areas,[106] the experience of individuals in those areas differs in important ways. In rural and other geographically remote areas, many people with mental illnesses have inadequate access to care, limited availability of skilled care providers, lower family incomes, and greater social stigma for seeking mental health treatment than their urban counterparts.[5; 107] As a result, rural residents with mental health needs:

- Enter care later in the course of their disease than their urban peers,
- Enter care with more serious, persistent, and disabling symptoms, and
- Require more expensive and intensive treatment response.[108]

For rural racial and ethnic minorities, these problems are compounded by their minority status and the dearth of culturally competent or bilingual providers in these medically underserved areas.

Compounding the problems of availability and access is the fact that rural Americans have lower family incomes and are less likely to have private health insurance benefits for mental health care than their urban counterparts.[109] Lack of coverage often occurs because small groups and individual purchasers dominate the rural health insurance marketplace, so insurance policies are more likely to have large deductibles and limited or no mental health coverage.[109]

Rural residents also have longer periods without insurance coverage than their urban peers and are less likely to seek services when they cannot pay for them.[110] For many rural Americans, the cost of mental health services — particularly prescription drugs — may be too high.

Rural areas also suffer from chronic shortages of mental health professionals. Virtually all of the rural counties in this country have a shortage of practicing psychiatrists, psychologists, and social workers.[111] Of the 1,669 Federally designated mental health professional shortage areas, more than 85% are rural.[112] These professional shortage problems are even worse for children and older adults.[111]

In addition, many primary care providers who work in rural areas are unprepared to diagnose or treat mental illnesses. Where general health providers in rural areas often use physician extenders, mental health extenders are not yet widely used. Where they are available, their services are frequently not reimbursed by insurance.

Another problem is that suicide rates are significantly higher among older men and Native American youth who live in rural areas. The rate of suicide appears to increase as the population becomes more rural.[21; 108; 113] While several factors may contribute to this phenomenon, researchers have yet to conduct in-depth analyses and studies across different geographic settings.

However, one certainty is that access to mental health care, attitudes toward mental illnesses, and cultural issues that influence whether people seek and receive care differ profoundly between rural and urban areas.

Achieving the Goal

RECOMMENDATION **3.1 Improve access to quality care that is culturally competent**

Culturally Competent Services Are Essential to Improve the Mental Health System

Culturally competent services are "the delivery of services that are responsive to the cultural concerns of racial and ethnic minority groups, including their language, histories, traditions, beliefs, and values."[16] Cultural competence in mental health is a general approach to delivering services that recognizes, incorporates, practices, and values cultural diversity. Its basic objectives are to ensure quality services for culturally diverse populations, including culturally appropriate prevention, outreach, service location, engagement, assessment, and intervention.[16]

Despite widespread use of the concept of cultural competence, research on putting the concept into practice and measuring its effectiveness is lacking. While critical indicators and standards for culturally competent care have been available for several years, the field has yet to systematically apply, measure, and link these standards to treatment outcomes. In addition, implementing these standards in the public sector has been slow.

> ***Culturally competent services*** – the delivery of services that are responsive to the cultural concerns of racial and ethnic minority groups, including their language, histories, traditions, beliefs, and values.

Nevertheless, many in the mental health field consider cultural competence to be essential to ensure quality of care, responsiveness of services, and renewed hope for recovery among ethnic and racial minorities. Empirical research is needed to assess the effectiveness of culturally competent practices. *(See Goal 5.)*

Meanwhile, mental health systems can respond to the needs of ethnic and racial minority populations by implementing existing standards, thus building trust, increasing cultural awareness, and responding to cultural and linguistic differences. In fact, programs that reflect the demographics, diversity, and values of a community—as shown by the Dallas school-based mental health model—are more likely to engage and keep racial and ethnic minorities in mental health services. (*See Figure 3.1.*)

The Commission recommends that States address and monitor racial and ethnic disparities in access, availability, quality, and outcomes of mental health services as part of their Comprehensive State Mental Health Plans. (*See Goal 2.*) This State-level strategic effort should include:

- Setting standards for culturally competent care;
- Collecting data to identify points of disparity;
- Evaluating services for effectiveness and consumer satisfaction;
- Developing collaborative relationships with culturally driven, community-based providers; and
- Establishing benchmarks and performance measures.

In addition, State plans should promote increased opportunities to include individuals from diverse cultural backgrounds in the mental health workforce. These opportunities should reflect the changing demographics and needs of communities for culturally and linguistically competent providers.

FIGURE 3.1. MODEL PROGRAM: A Culturally Competent School-Based Mental Health Program

Program	Dallas School-based Youth and Family Centers
Goal	To establish the first comprehensive, culturally competent, school-based program in mental health care in the 12th largest school system in the Nation. The program overcomes stigma and inadequate access to care for underserved minority populations.
Features	Annually serves the physical and mental health care needs of 3,000 low-income children and their families. The mental health component features partnerships with parents and families, treatment (typically 6 sessions), and follow-up with teachers. The well-qualified staff, who reflect the racial and ethnic composition of the population they serve (more than 70% Latino and African American), train school nurses, counselors, and principals to identify problems and create solutions tailored to meet each child's needs.
Outcomes	Improvements in attendance, discipline referrals, and teacher evaluation of child performance. [114] Preliminary findings reveal improvement in children's standardized test scores in relation to national and local norms.
Biggest challenge	To sustain financial and organizational support of collaborative partners despite resistance to change or jurisdictional barriers. Program's $3.5 million funding comes from the school district and an additional $1.5 million from Parkland Hospital.
How other organizations can adopt	Recognize the importance of mental health for the school success of all children, regardless of race or ethnicity. Rethink how school systems can more efficiently partner with and use State and Federal funds to deliver culturally competent school-based mental health services.
Sites	Dallas and Fort Worth, Texas

Finally, emerging evidence shows that collaborative efforts to bridge community health and mental health services are effective in the outreach, identification, engagement, and treatment for racial and ethnic minorities with mental illnesses.[16] Accordingly, national leadership is needed to improve the training of general medical practitioners and specialty mental health practitioners in caring for consumers at the intersection of these two parts of our overall health care system.

Therefore, the Commission recommends making strong efforts to recruit, retain, and enhance an ethnically, culturally, and linguistically competent mental health workforce throughout the country.

The Commission encourages government agencies, colleges, universities, professional associations, and minority advocacy groups to work together to address the workforce crisis in mental health services for racial and ethnic minority populations, especially for youth and their families. These efforts could include:

- Recruiting and retaining racial and ethnic minority and bilingual professionals;
- Developing and including curricula that address the impact of culture, race, and ethnicity on mental health and mental illnesses, on help-seeking behaviors, and on service use;
- Training and research programs targeting services to multicultural populations;
- Funding these training programs; and
- Engaging minority consumers and families in workforce development, training, and advocacy.

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The Commission recommends forming public-private partnerships for pre-service and in-service training. All Federally funded health and mental health training programs should explicitly include cultural competence in their curricula and training experiences. (*See Goal 5 for a broader recommendation on the mental health workforce.*)

The Commission recommends making strong efforts to recruit, retain, and enhance an ethnically, culturally, and linguistically competent mental health workforce throughout the country.

Given the significant role of faith-based organizations and leaders in the lives of many people, including ethnic and racial minorities, the Commission recommends enlisting their support and partnership in mental health care. This effort would involve working with the faith communities and leaders to help:

- Increase understanding of mental and physical health in their communities,
- Reduce stigma associated with mental disorders and problems,
- Encourage individuals and families to seek help,
- Collaborate with mental health providers, and
- When necessary, link people with appropriate services.

These faith-based leaders also may be critical in helping the mental health system and providers better understand the community.

RECOMMENDATION 3.2 Improve access to quality care in rural and geographically remote areas.

Rural Needs Must Be Met

To address the specific needs of the rural and geographically remote communities, the Commission encourages the U.S. Department of Health and Human Services (HHS) to convene a cross-agency workgroup to examine rural workforce issues to:

- Study current Federal workforce enhancement programs,
- Encourage a collaborative focus on rural mental health needs, and
- Oversee development of a rural mental health workforce strategy that includes using and supporting mid-level and alternative providers of mental health services.

The Commission recommends that the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Health Resources and Services Administration (HRSA) collaborate to support the training, deployment, and continuing education of rural mental health professionals. Such efforts should focus on strengthening the capacity and competency of the workforce to sustain an evidence-based service delivery system. (*Also see Goals 5 and 6.*)

In addition, the Commission recommends developing a Rural Mental Health Plan with specific, measurable targets and benchmarks. An important goal for this plan would be to fully integrate mental health into the existing infrastructure for rural public health. SAMHSA and HRSA should fully participate in developing this plan and should carefully consider the recommendations of the HHS Rural Task Force and the Initiative on Rural America. This national plan should closely align with States' Comprehensive Mental Health Plans. (See Recommendation 2.4.)

The Commission recommends that rural Americans receive increased access to mental health emergency response, early identification and screening, diagnosis, treatment and recovery services.

The Commission recognizes that affordable mental health care is a critical issue for rural

communities and residents. Federal and State agencies should explore policy options that enable rural individuals and small businesses to enter pools to purchase insurance so that they gain access to more affordable, high quality, health insurance. In addition, Federal agencies should ensure that new funding announcements do not place unrealistic non-Federal matching fund requirements on rural entities.

The emergence of telehealth offers access to care. Telehealth is using electronic information and telecommunications technologies to provide long-distance clinical health care, patient and professional health-related education, public health, and health administration. *(See Goal 6.)*

The Commission recommends that SAMHSA, HRSA, and the National Institutes of Health fund demonstration grants in rural areas to provide and evaluate the effectiveness of mental health services delivered by distant providers through new technologies. Enhanced coordination between funded telehealth systems and public mental health systems must be promoted.

The Commission supports this technology as one of the most promising means of improving access to specialty mental health care in underserved rural areas.

GOAL 4

Early Mental Health Screening, Assessment, and Referral to Services Are Common Practice.

RECOMMENDATIONS

- 4.1 Promote the mental health of young children.
- 4.2 Improve and expand school mental health programs.
- 4.3 Screen for co-occurring mental and substance use disorders and link with integrated treatment strategies.
- 4.4 Screen for mental disorders in primary health care, across the life span, and connect to treatment and supports.

Understanding the Goal

Early Assessment and Treatment Are Critical Across the Life Span

For consumers of all ages, early detection, assessment, and linkage with treatment and supports can prevent mental health problems from compounding and poor life outcomes from accumulating. Early intervention can have a significant impact on the lives of children and adults who experience mental health problems.

Emerging research indicates that intervening early can interrupt the negative course of some mental illnesses and may, in some cases, lessen long-term disability. New understanding of the brain indicates that early identification and intervention can sharply improve outcomes and that longer periods of abnormal thoughts and behavior have cumulative effects and can limit capacity for recovery.[115]

If Untreated, Childhood Disorders Can Lead to a Downward Spiral

Early childhood is a critical period for the onset of emotional and behavioral impairments.[115] In 1997, the latest data available, nearly 120,000 preschoolers under the age of six — or 1 out of 200 — received mental health services.[116] Each year, young children are expelled from preschools and childcare facilities for severely disruptive behaviors and emotional disorders.

Since children develop rapidly, delivering mental health services and supports early and swiftly is necessary to avoid permanent consequences and to ensure that children are ready for school. Emerging neuroscience highlights the ability of environmental factors to shape brain development and related behavior. Consequently, early detection, assessment, and links with treatment and supports can prevent mental health problems from worsening.

Without intervention, child and adolescent disorders frequently continue into adulthood. For example, research shows that when children with co-existing depression and conduct disorders become adults, they tend to use more health care services and have higher health care costs than other adults.[117] If the system does not appropriately screen and treat them early, these childhood disorders may persist and lead to a downward spiral of school failure, poor employment opportunities, and poverty in adulthood. No other illnesses damage so many children so seriously.[118]

One of the many factors that can affect the emotional health of young children is the mental health status of their parents. For example, depression among young mothers has been shown to influence the mental health of their young children.[119; 120] These findings are significant because mental disorders that occur before the age of six can interfere with critical emotional, cognitive, and physical development, and can predict a lifetime of problems in school, at home, and in the community.[121]

Early detection, assessment, and links with treatment and supports can prevent mental health problems from worsening.

Schools Can Help Address Mental Health Problems

Currently, no agency or system is clearly responsible or accountable for young people with serious emotional disturbances. They are invariably involved with more than one specialized service system, including mental health, special education, child welfare, juvenile justice, substance abuse, and health.

The mission of public schools is to educate all students. However, children with serious emotional disturbances have the highest rates of school failure. Fifty percent of these students drop out of high school, compared to 30% of all students with disabilities.[81] Schools are where children spend most of each day. While schools are primarily concerned with education, mental health is essential to learning as well as to social and emotional development. Because of this important interplay between emotional health and school success, schools must be partners in the mental health care of our children.

Schools are in a key position to identify mental health problems early and to provide a link to appropriate services. Every day more than 52 million students attend over 114,000 schools in the U.S. When combined with the six million adults working at those schools, almost one-fifth of the population passes through the Nation's schools on any given weekday.[122] Clearly, strong school mental health programs can attend to the health and behavioral concerns of students, reduce unnecessary pain and suffering, and help ensure academic achievement.

People with Co-occurring Disorders Are Inadequately Served

Early intervention and appropriate treatment can also reduce pain and suffering for children and adults who have or who are at risk for co-occurring mental and addictive disorders.[115; 123] Seven to ten million people in the United States have at least one mental disorder in addition to an alcohol or drug abuse disorder.[124; 125] Too often, these individuals are treated for only one of the two disorders — if they are treated at all.

In his speech announcing the Commission, the President used an example that affirms this point. The President spoke of:

> "... a 14-year-old boy who started experimenting with drugs to ease his severe depression. This former honor student became a drug addict. He dropped out of school, was incarcerated six times in 16 years. Only two years ago, when he was 30 years old, did the doctors finally diagnose his condition as bipolar disorder, and he began a successful program ..."

Co-occurring substance use and mental disorders can occur at any age. Research suggests that as many as half of the adults who have a diagnosable mental disorder will also have a substance use disorder at some point during their lifetime.[106; 126]

A substantial number of children and adolescents also have co-occurring mental illnesses and substance use disorders.[124] If one co-occurring disorder remains untreated, both usually get worse. Additional complications often arise, including the risk for other medical problems, unemployment, homelessness, incarceration, suicide, and separation from families and friends.[124]

Older adults are at risk of developing both depression and alcohol dependence for perhaps the first time in their lives. This phase of the life cycle has new risk factors for both of these disorders. The number of older adults with mental illnesses is expected to double to 15 million in the next 30 years.[127] Mental illnesses have a significant impact on the health and functioning of older people and are associated with increased health care use and higher costs.[128-130] The current mental health service system is inadequate and unprepared to address the needs associated with the anticipated growth in the number of older people requiring treatment for late-life mental disorders.[127]

Individuals with co-occurring disorders challenge both clinicians and the treatment delivery system. They most frequently use the costliest services (emergency rooms, inpatient facilities, and outreach intensive services), and often have poor clinical outcomes.[124] The combination of problems increases the severity of their psychiatric symptoms and the likelihood for suicide attempts, violent behaviors, legal problems, medical problems, and periods of homelessness.[124]

Studies show that few providers or systems that treat mental illnesses or substance use disorders adequately address the problem of co-occurring disorders. Only 19% of people who have co-occurring serious mental illnesses and substance dependence disorders are treated for both disorders; 29% are not treated for either problem. For people with less serious mental illnesses and substance dependence problems, the pattern of under-treatment is even worse. Most (71%) receive no treatment; only 4% receive treatment for both disorders.[124] The same pattern of under-treatment holds for youth with co-occurring disorders.[131]

Widespread barriers impede effective treatment for people with co-occurring disorders at all levels, including Federal, State, and local governments, and individual treatment agencies.

Mental Health Problems Are Not Adequately Addressed in Primary Care Settings

People with mental health disorders are routinely seen in primary care settings. The Epidemiologic Catchment Area Study, conducted in the early 1980s, found that while people with common mental illnesses had some contact with primary care services, few received specialty mental health care. About half of the care for common mental disorders is delivered in general medical settings.[7; 132; 133] Primary care providers actually prescribe the majority of psychotropic drugs for both children and adults. While primary care providers appear positioned to play a fundamental role in addressing mental illnesses, there are persistent problems in the areas of identification, treatment, and referral.

Despite their prevalence, mental disorders often go undiagnosed, untreated, or under-treated in primary care. Primary care providers' rates of recognition of mental health problems are still low, although the number identified is increasing. When mental illnesses are identified, they are not always adequately treated in the primary care setting, and referrals from primary care to specialty mental health treatment are often never completed.

Despite their prevalence, mental disorders often go undiagnosed, untreated, or under-treated in primary care.

While effective treatments exist for most common mental disorders, studies have shown that many consumers seen in primary care settings do not receive them.[7; 134] Even in the 1990s, most adults with depression, anxiety, and other common mental disorders did not receive appropriate care in primary care settings.[7; 134] Older adults, children and adolescents, individuals from ethnic minority groups, and uninsured or low-income patients seen in the public sector are particularly unlikely to receive care for mental disorders.[5; 16]

Of individuals who die by suicide, approximately 90% had a mental disorder,[21] and 40% of these individuals had visited their primary care doctor within the month before their suicide.[135; 136] During visits in the primary care setting, the question of suicide was seldom raised.

A significant percentage of patients in primary care shows signs of depression,[137] yet up to half go undetected and untreated.[138] This is especially problematic for women,[139] people with a family history of depression,[140] the unemployed,[141] and those with chronic disease,[141] all of whom are at increased risk for depression.

A significant percentage of patients in primary care shows signs of depression, yet up to half go undetected and untreated.

Of all the children they see, primary care physicians identify about 19%with behavioral and emotional problems.[142] While these providers frequently refer children for mental health treatment, significant barriers exist to referral, including lack of available specialists, insurance restrictions, appointment delays, and stigma. In one study, 59% of youth who were referred to specialty mental health care never made it to the specialist.[142]

Finally, it is noteworthy that there is a parallel problem in specialty mental health care. Specialty mental health providers often have difficulty providing adequate medical care to consumers with co-existing mental and physical illnesses.[174] Given that individuals with serious mental illnesses, such as schizophrenia, have high levels of non-psychiatric medical illnesses and excess medical mortality, this is also a troubling situation.[143]

Achieving the Goal

RECOMMENDATION 4.1 Promote the mental health of young children.

Early Detection Can Reduce Mental Health Problems

Early detection and treatment of mental disorders can result in a substantially shorter and less disabling course of illness.[144; 145] As the mental health field becomes increasingly able to identify the early antecedents of mental illnesses at any age, interventions must be implemented, provided in multiple settings, and connected to treatment and supports.

Early interventions, such as the Nurse-Family Partnership (*See Figure 4.1.*), and educational efforts can help a greater number of parents, the public, and providers learn about the importance of the first years of a child's life and how to establish a foundation for healthy social and emotional development.

Quality screening and early intervention should occur in readily accessible, low-stigma settings, such as primary health care facilities and schools, and in settings where a high level of risk for mental health problems exists, such as juvenile justice and child welfare.

FIGURE 4.1. MODEL PROGRAM: Intervening Early to Prevent Mental Health Problems

Program	Nurse-Family Partnership
Goal	To improve pregnancy outcomes by helping mothers adopt healthy behavior, improve child health and development, reduce child abuse and neglect, and improve families' economic self-sufficiency.
Features	A nurse visits the homes of high-risk women when pregnancy begins and continues for the first year of the child's life. The nurse adheres to visit-by-visit protocols to help women adopt healthy behaviors and to responsibly care for their children. In many states, Nurse-Family Partnership programs are funded as special projects or through State appropriations.
Outcomes	*For mothers:* 80% reduction in abuse of their children, 25% reduction in maternal substance abuse, and 83% increase in employment. *For children (15 years later):* 54% to 69% reduction in arrests and convictions, less risky behavior, and fewer school suspensions and destructive behaviors. This is the only prevention trial in the field with a randomized, controlled design and 15 years of follow-up. The program began in rural New York 20 years ago and its benefits have been replicated in Denver and in minority populations in Memphis.[146-148]
Biggest challenge	To preserve the program's core features as it grows nationwide. The key feature is a trained nurse, rather than a paraprofessional, who visits homes. A randomized, controlled trial found paraprofessionals to be ineffective.[149]
How other organizations can adopt	Modify requirements of Federal programs, where indicated, to facilitate adopting this successful, cost-effective model.
Sites	270 communities in 23 states.
For additional information	http://www.nccfc.org/nurseFamilyPartnership.cfm

The Commission suggests a national focus on the mental health needs of young children and their families that includes screening, assessment, early intervention, treatment, training, and financing services. The national focus will:

- Build on coordination mechanisms already in place, such as Part C of the Individuals with Disabilities Education Act (IDEA); and
- Expand the coordination of services for children ages 3 through 21 for those who qualify for services under Part B of IDEA, thus building capacity for improved and increased services in communities.

A coordinated, national approach to these issues will help eliminate social and emotional barriers to learning and will promote success in school and in other community settings for young children. This effort may involve collaborations among parents, mental health providers, and early childhood and child care programs. Other important dimensions of the approach will include:

- Training a workforce skilled in treating young children and their families;
- Training primary health providers to screen for and recognize early signs of emotional and behavioral problems and to offer connections to appropriate interventions;
- Eliminating barriers to coverage, such as a required psychiatric diagnosis when an alternative diagnosis that minimizes labeling and stigma is more appropriate; and
- Including "social and emotional check-ups" in primary health care.

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The IDEA specifically provides for a statewide, comprehensive, interagency system for early prevention services for children with disabilities from birth to 3 years old who have a developmental delay and physical, cognitive, communication, social or emotional, or adaptive development problem, or have a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay.

More effort is needed to heighten public awareness of the developmental requirements for children's social and emotional well-being — just as public awareness of the early developmental and educational needs for reading skills has been increased through public and private initiatives.

When children with disabilities reach age 3, they may be eligible for services under Part B of IDEA if they have one of the specified impairments and if, because of the impairment, they need special education and related services. However, services and other resources for children who have emotional and mental health issues are sometimes less readily available with respect to workforce, interventions, and financing, than other services, such as speech and language therapy or physical therapy.

Addressing the mental health of young children may also involve providing information, supports, and treatment for parents. For the young child, treating the parents' mental health problems also benefits the child.[150]

RECOMMENDATION **4.2 Improve and expand school mental health programs.**

Schools Should Have the Ability to Play a Larger Role in Mental Health Care for Children

Growing evidence shows that school mental health programs improve educational outcomes by decreasing absences, decreasing discipline referrals, and improving test scores.[114] The key to improving academic achievement is to identify mental health problems early and, when needed, provide appropriate services or links to services. The extent, severity, and far-reaching consequences make it imperative that our Nation adopt a comprehensive, systematic approach to improving the mental health status of children.

Clearly, school mental health programs must provide any screening or treatment services with full attention to the confidentiality and privacy of children and families. The Columbia University TeenScreen® program provides a model for early intervention. (*See Figure 4.2.*)

The Commission recommends that Federal, State, and local child-serving agencies fully recognize and address the mental health needs of youth in the education system. They can work collaboratively with families to develop, evaluate, and disseminate effective approaches for providing mental health services and supports to youth in schools along a critical continuum of care. This continuum includes education and training, prevention, early identification, early intervention, and treatment.

FIGURE 4.2. MODEL PROGRAM: Screening Program for Youth

Program	Columbia University TeenScreen® Program
Goal	To ensure that all youth are offered a mental health check-up before graduating from high school. TeenScreen® identifies and refers for treatment those who are at risk for suicide or suffer from an untreated mental illness.
Features	All youngsters in a school, with parental consent, are given a computer-based questionnaire that screens them for mental illnesses and suicide risk. At no charge, the Columbia University TeenScreen® Program provides consultation, screening materials, software, training, and technical assistance to qualifying schools and communities. In return, TeenScreen® partners are expected to screen at least 200 youth per year and ensure that a licensed mental health professional is on-site to give immediate counseling and referral services for youth at greatest risk. The Columbia TeenScreen® Program is a not-for-profit organization funded solely by foundations. When the program identifies youth needing treatment, their care is paid for depending on the family's health coverage.
Outcomes	The computer-based questionnaire used by TeenScreen® is a valid and reliable screening instrument.[151] The vast majority of youth identified through the program as having already made a suicide attempt, or at risk for depression or suicidal thinking, are not in treatment.[152] A follow-up study found that screening in high school identified more than 60% of students who, four to six years later, continued to have long-term, recurrent problems with depression and suicidal attempts.[153]
Biggest challenge	To bridge the gap between schools and local providers of mental health services. Another challenge is to ensure, in times of fiscal austerity, that schools devote a health professional to screening and referral.
How other organizations can adopt	The Columbia University TeenScreen® Program is pilot-testing a shorter questionnaire, which will be less costly and time-consuming for the school to administer. It is also trying to adapt the program to primary care settings.
Website	www.teenscreen.org
Sites where implemented	69 sites (mostly middle schools and high schools) in 27 States

The *No Child Left Behind Act of 2001*[154] is designed to help all children, including those with serious emotional disturbances reach their optimal potential and achievement. To fulfill the promise of this Act, schools must work to remove the emotional, behavioral, and academic barriers that interfere with student success in school. Consequently, it is critical to strengthen mental health programs in schools. This effort may involve:

- Working with parents, local providers, and local agencies to support screening, assessment, and early intervention;
- Ensuring that mental health services are part of school health centers;
- Ensuring that these services are Federally funded as health, mental health, and education programs;

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- Building on a recommendation from the President's Commission on Excellence in Special Education[155] to implement empirically supported prevention and early intervention approaches at the school district, local school, classroom, and individual student levels; and
- Creating a State-level structure for school-based mental health services to provide consistent State-level leadership and collaboration between education, general health, and mental health systems.

Since the IDEA requires that a variety of professionals collaborate in the school and in the community, the Commission urges that coordinating services be regarded as a "related service" in the child's Individual Education Plan (IEP). In developing the IEP, there should be a stronger family focus and youth involvement and support. The training and research funds designated in this Act should be considered for use to train teachers, related services professionals, and parents to recognize signs of emotional and behavioral problems in children, make appropriate referrals for assessment and services and classroom accommodations, and implement and evaluate evidence-based school mental health interventions.

On a related topic, the Commission recognizes the particular challenges for youth in transition from adolescence to adulthood. IDEA has transition requirements beginning at age 14, but to date, these requirements have not resulted in acceptable post-school outcomes.

Studies show that approximately 42% of students with serious emotional disturbances graduate from high school as opposed to 57% of students with other disabilities.[81] Schools and local mental health agencies could improve their collaboration and use of evidence-based practices to develop transition-to-work services so that children with serious emotional disorders can move successfully from school to employment or to post-secondary education.

RECOMMENDATION 4.3 Screen for co-occurring mental and substance use disorders and link with integrated treatment strategies.

Treatment for Co-occurring Disorders Must Be Integrated

Integrated treatment is a means of coordinating both substance abuse and mental health interventions to treat the whole person more effectively. From studies and first-hand experiences, many researchers and clinicians in these fields believe that both disorders must be addressed as primary illnesses and treated as such. Integrated treatment can improve client engagement, reduce substance abuse, improve mental health status, and reduce relapses for all age groups.[124]

Integrated services should appear seamless to the individual who seeks and receives care. Mental health and substance abuse treatment can be integrated by one clinician, two or more clinicians working together, one program, or a network of services.

A key challenge to developing integrated treatment programs is overcoming the traditional separation between mental health and substance abuse treatment.

Integrated treatment often involves other systems as well, because individuals with co-occurring disorders typically have a wide range of health and social service needs. For example, children in the juvenile justice system are at high risk for co-occurring mental and substance abuse disorders.[156] Similarly, in the child welfare system, research strongly demonstrates that children in foster care at a high-risk for maladaptive outcomes, including socio-emotional, behavioral, and psychiatric problems warranting mental health treatment and supports.[157-159]

A key challenge to developing integrated treatment programs is overcoming the traditional separation between mental health and substance abuse treatment. At least 36 States are attempting some change to their systems by addressing this problem through creative leadership with a sustained vision and by engaging strong local stakeholder support — including consumers and families — in program design and advocacy.[124] However, much remains to be accomplished.

Studies of these efforts have shown that State and local regulatory issues and impediments to multiple State and local funding streams continue as major barriers to changing the systems. The Commission commends the Substance Abuse and Mental Health Services Administration (SAMHSA) for its *Report to Congress on the Prevention and Treatment of Co-occurring Substance Abuse Disorders and Mental Disorders* and supports the five-year blueprint for action contained in the report.[124]

The Commission supports implementing systematic screening procedures to identify mental health and substance use problems and treatment needs in all settings in which children, youth, adults, or older adults are at high risk for mental illnesses or in settings in which a high occurrence of co-occurring mental and substance use disorders exists. In addition to specialty mental health and substance abuse treatment settings, screening for co-occurring disorders should be implemented when an individual enters the juvenile or criminal justice systems, child welfare system, homeless shelters, hospitals, senior housing, long-term care facilities, nursing homes, and other settings where populations are at high risk. Screening should also occur periodically after an individual enters any of these facilities.

When mental health problems are identified, children, youth, adults, and older adults should be linked with appropriate services, supports, or diversion programs. Additionally, given the high incidence of substance use disorders among parents of children in the child welfare system, where indicated, these parents should be screened for co-occurring disorders and linked with appropriate treatment and supports.

The Commission supports coordinated and, where appropriate, integrated mental health and substance abuse screening, assessment, early intervention, and treatment for co-occurring disorders in all Federally funded adult and child health and human services, criminal and juvenile justice programs, and veteran's services. Health and mental health training programs that receive HHS funding should include co-occurring disorders in curriculum design and training experiences.

The Center for Medicare and Medicaid Services (CMS) should be encouraged to develop and implement policy guidance to promote access and use of covered services by Medicaid and Medicare beneficiaries with co-occurring mental and substance use disorders.

RECOMMENDATION 4.4 Screen for mental disorders in primary health care, across the life span, and connect to treatment and supports.

Expand Screening and Collaborative Care in Primary Care Settings

The Commission suggests that collaborative care models should be widely implemented in primary health care settings and reimbursed by public and private insurers. Numerous studies have documented the effectiveness of collaborative care models.[160-162] Expanded screening and collaborative care models, such as the Collaborative Care Model for treating late-life depression in primary care settings (*See Figure 4.3.*), could save lives.

The Commission notes that the Federal government could better coordinate the funding and the clinical care provided by publicly funded

FIGURE 4-3. MODEL PROGRAM: Collaborative Care for Treating Late-Life Depression in Primary Care Settings

Program	IMPACT—Improving Mood: Providing Access to Collaborative Treatment for Late Life Depression
Goal	To recognize, treat, and prevent future relapses in older patients with major depression in primary care. About 5% -10% of older patients have major depression, yet most are not properly recognized and treated. Untreated depression causes distress, disability, and, most tragically, suicide.
Features	Uses a team approach to deliver depression care to elderly adults in primary care setting. Older adults are given a choice of medication from a primary care physician or psychotherapy with a mental health provider. If they do not improve, their level of care is increased by adding supervision by a mental health specialist.
Outcomes	The intervention, compared to usual care, leads to higher satisfaction with depression treatment, reduced prevalence and severity of symptoms, or complete remission.[163]
Biggest challenge	To ensure that the intervention is readily adapted from the research setting into the practice setting.
How other organizations can adopt	Be receptive to organizational changes in primary care and devise new methods of reimbursement.
Sites	Study sites in California, Texas, Washington, North Carolina, Indiana

community health clinics to consumers with multiple conditions, including physical, mental, and co-occurring substance use disorders. This effort would include improved coordination of care between Health Resources and Services Administration-funded community health clinics and SAMHSA- or State-supported community mental health centers.

Expanded screening and collaborative care models could save lives.

The Commission recommends that Medicare, Medicaid, the Department of Veterans Affairs, and other Federal and State-sponsored health insurance programs and private insurers identify and consider payment for core components of evidence-based collaborative care, including:

- Case management,
- Disease management,
- Supervision of case managers, and
- Consultations to primary care providers by qualified mental health specialists that do not involve face-to-face contact with clients.

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GOAL 5 Excellent Mental Health Care Is Delivered and Research Is Accelerated.

RECOMMENDATIONS

5.1 Accelerate research to promote recovery and resilience, and ultimately to cure and prevent mental illnesses.

5.2 Advance evidence-based practices using dissemination and demonstration projects and create a public-private partnership to guide their implementation.

5.3 Improve and expand the workforce providing evidence-based mental health services and supports.

5.4 Develop the knowledge base in four understudied areas: mental health disparities, long-term effects of medications, trauma, and acute care.

Understanding the Goal

The Delay Is Too Long Before Research Reaches Practice

Over the years, research has yielded important advances in our knowledge of the brain, behavior, and effective treatments and service delivery strategies for many mental disorders. An array of evidence-based medications and psychosocial interventions — typically used together — now allows successful treatment of most mental disorders. Despite these advances in science, many Americans are not benefiting from these investments.[6; 7]

Far too often, treatments and services based on rigorous clinical research languish for years rather than being used effectively at the earliest opportunity. According to the Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*,[9] the lag between discovering effective forms of treatment and incorporating them into routine patient care is unnecessarily long, lasting about 15 to 20 years.[164]

Even when these discoveries become routinely available at the community level, too often the clinical practice is highly uneven and inconsistent with the original treatment model that was shown to be effective.[165] Extended time to conduct efficacy and other value-determining tests ensures that safeguards are in place for these proven and emerging remedies. However, follow-up be allowed to research on already proven interventions should not be allowed to hinder efforts to put that knowledge, service, treatment, and supportive service into clinical practice.

Too Few Benefit from Available Treatment

Effective, state-of-the-art treatments vital for quality care and recovery are now available for most serious mental illnesses and serious emotional disorders.[18] Yet these new effective practices are not being used to benefit countless people with mental illnesses. The mental health field has developed *evidence-based practices* (EBPs) — a range of treatments and services whose effectiveness is well documented. A partial list of EBPs includes:

- Specific medications for specific conditions,
- Cognitive and interpersonal therapies for depression,
- Preventive interventions for children at risk for serious emotional disturbances,
- Treatment foster care,
- Multi-systemic therapy,
- Parent-child interaction therapy,
- Medication algorithms,
- Family psycho-education,
- Assertive community treatment, and
- Collaborative treatment in primary care.

Evidence-based practice (EBP) is defined by the Institute of Medicine as – the integration of best-researched evidence and clinical expertise with patient values.[9]

Emerging best practices – treatments and services that are promising but less thoroughly documented than evidence-based practices.

Along with EBPs, the mental health field has also developed promising but less thoroughly documented *emerging best practices*, such as:

- Consumer operated services,
- Jail diversion and community re-entry programs,
- School mental health services,
- Trauma-specific interventions,
- Wraparound services,
- Multi-family group therapies, and
- Systems of care for children with serious emotional disturbances and their families.

Despite this range of effective, state-of-the-art treatments and best practices, many interventions and supports do not reach the people who need them because of:

- Complex reimbursement policies (if payment for the treatments is even allowable),
- The growing crisis in workforce training,
- The shortage of qualified professionals, and
- The need for more research on putting new and proven methods into practice more rapidly.

The Texas Medication Algorithm Project illustrates an evidence-based practice that results in better consumer outcomes, including reduced symptoms, fewer and less severe side effects, and improved functioning.[166-168] (*See Figure 5.1.*) However, too few consumers benefit from this practice because it is not widely used.

FIGURE 5-1. MODEL PROGRAM: Quality Medications Care for Serious Mental Illnesses

Program	Texas Medication Algorithm Project (TMAP)
Goal	To ensure quality care for people with serious mental illnesses by developing, applying, and evaluating medication algorithms. An algorithm is a step-by-step procedure in the form of a flow chart to help clinicians deliver quality care through the best choice of medications and brief assessment of their effectiveness. The target population is people with serious mental illnesses served by public programs.
Features	Development of algorithms as well as development of consumer education materials and other tools for treating serious mental illnesses. Public sector-university collaboration with support of stakeholders, education and technical assistance, and administrative supports to serve the most medically complex patients. Early phases of the project developed the algorithms and tested the benefits of their use; the program's latest phases focus on implementing TMAP in mental health treatment settings throughout the State.
Outcomes	The algorithm package implemented by Texas was more effective than treatment-as-usual for depression, bipolar disorder and schizophrenia. It reduced symptoms, side effects and improved functioning.[166-168] The package's benefit for reducing incarceration is being studied. In addition, medication algorithms have been developed for treating children with depression or attention deficit hyperactivity disorder (AD/HD). TMAP algorithms have also been adapted to treat adult consumers who have co-occurring mental and substance use disorders.
Biggest Challenge	To ensure that the entire algorithm package — patient education, frequent medical visits, medication availability, and consultation — is properly implemented in other States and localities.
How other organizations can adopt	Conduct an active planning process, including meetings with stakeholders, to examine what organizational changes are needed to make the algorithm work best.
Sites	Texas; Nevada; Ohio; Pennsylvania; South Carolina; New Mexico; Atlanta and Athens, GA; Louisville, Kentucky; Washington, D.C.; San Diego County, CA; and private sector in Denver, Colorado.

Reimbursement Policies Do Not Foster Converting Research to Practice

The complexities and limitations in paying for many well-established, evidence-based practices for children and adults cause the quality of mental health services to vary greatly. In particular, Medicaid, Medicare, and private payers must keep current with advances in evidence-based practices, continuously examining practice to inform reimbursement policies.

As promising new findings are conveyed from the research community into the hands of front-line providers, policies and financing criteria at the Federal, State, and local levels must provide incentives to support adopting and using these new findings. In the current system, some disincentives exist in cases where private insurance, Medicaid, or Medicare may reimburse for a particular EBP, but the complexity of the coverage rules makes implementing it difficult. Fee-for-service reimbursement systems for Medicaid, Medicare, and other payers do not allow providers to bill for essential components of many EBP programs, such as flexible case management, non-face-to-face services, or home visits.

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Many private insurers do not cover these effective supports, services, treatments or practices. While it is possible for Medicaid to cover many of these practices, the only way to access reimbursement for them presently is to navigate the system expertly enough to obtain approval to provide these services under an option or a waiver.

Serious Workforce Problems Exist

The Commission heard consistent testimony from consumers, families, advocates, and public and private providers about the "workforce crisis" in mental health care. Today not only is there a shortage of providers, but those providers who are available are not trained in evidence-based and other innovative practices. This lack of education, training, or supervision leads to a workforce that is ill-equipped to use the latest breakthroughs in modern medicine.

> Despite the recognized importance of culturally relevant services, training curricula generally lack an adequate focus on developing cultural competence.

Although the supply of well-trained mental health professionals is inadequate in most areas of the country, rural areas are especially hard hit.[112] In addition, particular shortages exist for mental health providers who serve children, adolescents, and older Americans.[105; 169; 170]

Another challenge in the mental health system is the condition of some education programs. While some graduate programs have led the field in developing and disseminating evidence-based practices, many others have not kept pace with dramatic technological developments in delivering care. Continuing education programs routinely employ teaching methods that have been demonstrated, through research, to have little effect on provider behavior or impact on consumer outcomes.[171] Also, substantive training in the evidence-based treatment of mental illnesses tends *not* to be offered to critical segments of the workforce that have an enormous role in direct care including bachelor-level staff, paraprofessionals, primary care providers, consumers, and families.[171]

Despite the recognized importance of culturally relevant services, training curricula generally lack an adequate focus on developing cultural competence. Racial, ethnic, and linguistic minorities remain significantly under-represented in the current workforce.[1; 104; 105] *(See Goal 3 for a related discussion.)*

As concepts of recovery and resiliency become key principles in mental health care, education and training programs must incorporate these concepts in their curricula, training materials, and experiences.

Four Areas Have Not Been Studied Enough

The knowledge base in the mental health system is lacking sufficient information in at least four areas:

- Minority disparities in mental health research,
- The long-term effects of medications,
- The impact of trauma, and
- Acute care.

Disparities in Mental Health Research

While many types of disparities exist in mental health care, American Indians, Alaskan Natives, African Americans, Asian Americans, Pacific Islanders, and Hispanic Americans bear a disproportionately high burden of disability from mental health disorders, not because of greater prevalence or severity of illnesses in these populations, but because they receive less care and poorer quality of care.[1] Similarly, these groups are significantly under-represented in mental health research and mental health service delivery.[1] (*See Goal 3 for a related discussion.*)

Long-term Use of Medications

Breakthroughs in developing the next generation of medications provide hope for treatment and recovery from mental illnesses. The discovery of effective treatments using medications currently on the market is also encouraging. However, since

these medications are treatments and not cures, some individuals with chronic illnesses, including children, are expected to use these medications over an extended period of time. Knowledge of the clinical and economic effects of these medications is limited because systematically evaluating the maintenance use of medications is not required for FDA approval. Consequently, long-term effects have not been well studied for many psychotropic medications.

Long-term effects have not been studied well enough for many psychotropic medications.

The Impact of Trauma

Stressful life events or the manifestation of mental illnesses can upset the balance most adults seek in life, resulting in distress and dysfunction. Severe or life-threatening traumatic events experienced in childhood or adulthood sometimes lead to emotional and behavioral reactions that jeopardize mental health. The likelihood of developing post-traumatic stress disorder (PTSD) is related to pre-trauma vulnerability, magnitude of the event, preparedness for the event, and the quality of care after the event.[172]

Urban and Native American youth are more likely to be exposed to violence,[173] while women are twice as likely to develop PTSD after they are exposed to life-threatening trauma.[174] The mental health field lacks sufficient information about dealing with trauma and its effects on different populations. Also, few treatments specifically for adult survivors of childhood abuse have been studied in randomized controlled trials.[175]

Acute Care

Shortages exist in the availability of psychiatric beds and other levels of acute care in many regions of the country.[176-178] Too often the short-term psychiatric inpatient care and emergency services in hospitals are used as the first contact for uninsured and under-insured populations. Other crisis and urgent care service settings — 24-hour care in residential treatment facilities for children, mobile crisis teams, and respite hostels — are also forms of acute care facilities. This important segment of the health care delivery system lacks essential national data, shows evidence of treatment gaps in many regions, and lacks consistent clinical standards.

Achieving the Goal

RECOMMENDATION **5.1 Accelerate research to promote recovery and resilience, and ultimately to cure and prevent mental illnesses.**

Speed Research on Treatment and Recovery

The Commission's study has taken place in a context of enormous progress and accomplishment in the scientific study of effective treatments and services in mental health care. Research is having a significant impact on the effectiveness of the mental health care delivery system and, given the significant co-occurrence of mental disorders with general medical illnesses, on the overall quality of health care available in the U.S. Progress in understanding the causes of disorders of the mind and the brain will accelerate discovering new treatments and approaches to recovery while raising the possibility that mental illnesses will ultimately be cured or prevented.

A commitment is necessary to speed the findings of research to treatment and services providers as well as to the public as a whole. An on-going dialogue among researchers, providers, consumers, and families is vital to address research priorities, study designs, interpretation of results, and the dissemination of findings. The Commission recommends making a national commitment to continue discovering and applying improved treatments and services in mental health care, as well as creating a research program with a

long-term goal of developing cures for major mental illnesses.

In addition, the National Institutes of Health (NIH), and the Substance Abuse and Mental Health Services Administration (SAMHSA) should partner with the National Institute on Disability and Rehabilitation Research to promote research on factors contributing to rehabilitation and recovery from mental illnesses.

RECOMMENDATION **5.2 Advance evidence-based practices using dissemination and demonstration projects and create a public-private partnership to guide their implementation.**

Bridge the Gap Between Science and Service

To further advance treatment and prevention in mental health care, the Nation must continue to invest in research at all levels. These research activities must include a serious "science-to-services" endeavor, resulting in delivering the very best evidence-based practices to consumers in a timely way.

The Nation must have a more effective system to identify, disseminate, and apply proven treatments or evidenced-based practices (EBPs) to mental health care. Systematic approaches to bring scientific discovery to service providers, consumers, and families must be emphasized more. Medicaid demonstration initiatives are an essential tool to inform policy makers and Federal payers about the effectiveness and fiscal impact of health care innovations. As these new practices are identified, dissemination projects evaluating best methods for widespread implementation are needed.

Technical assistance on the importance of moving evidence-based practices into the field must accompany any reforms. This support will help alleviate the lag time between discovery and delivery, thus, bringing about a healthier, more robust population.

The Commission recommends that the Department of Health and Human Services provide leadership to evaluate implementing evidence-based interventions through dissemination projects. The Federal government should initiate and sustain a public-private partnership, with involvement and support from private foundations, advocacy groups, and professional organizations. The goal of this partnership would be to:

- Advance knowledge,
- Disseminate findings,
- Facilitate workforce development,
- Recognize those treatments and services that should be considered evidence-based, and
- Ensure they are implemented with adequate financial support.

The partnership should comprise all stakeholders including providers, consumers, and families. It should guide and oversee many activities that are currently scattered throughout the public and private sectors, thus eliminating inefficient duplication and encouraging collaboration on potentially beneficial issues. This leadership is needed to bridge the gap between science and service.

The Commission encourages continuing and expanding the collaboration between NIH and SAMHSA to conduct rigorous peer-reviewed research. They should use both quantitative and qualitative research methods to increase our knowledge about the most effective means of disseminating and promoting evidenced-based practices. These HHS agencies have already begun a formal "science to services" process to further develop and expand evidenced-based practices in the field. They have jointly funded a grant program for State mental health agencies to begin developing the infrastructure to conduct research alongside dissemination efforts. The process should be part of a comprehensive strategy moving from science to service and from the field back to science.

To promote efficient and cost-effective practices for improved consumer outcomes, the field needs more rigorous studies of EBP dissemination efforts. One such effort is ongoing. National Institute of Mental Health and SAMHSA are collaborating to support a study on implementing the Family Critical Time Intervention Model with homeless families and their children. (*See Figure 5.2.)*

The Commission concludes that national leadership must overcome the fragmentation and blurring of responsibility for translating the science of mental health into clinical practice.

Toward this end, mental health field must expand its efforts to develop and test new treatments and practices, to promote awareness of and improve training in evidence-based practices, and to better finance those practices.

FIGURE 5-2. MODEL PROGRAM: Critical Time Intervention with Homeless Families

Program	Family Critical Time Intervention model (FCTI). The program is jointly funded by NIMH and the Center for Mental Health Services/Center for Substance Abuse Treatment Homeless Families Program.
Goal	To apply effective, time-limited, and intensive intervention strategies to provide mental health and substance abuse treatment, trauma recovery, housing, support and family preservation services to homeless mothers with mental illnesses and substance use disorders who are caring for their dependent children.
Features	The Critical Time Intervention model (CTI) was developed in New York City as a program to increase housing stability for persons with severe mental illnesses and long-term histories of homelessness. Its principle components are rapid placement in transitional housing, fidelity to a Critical Time Intervention CTI model for families (i.e., provision of an intensive, 9-month case management intervention, with mental health and substance use treatments), a focused team approach to service delivery, with the aim of reducing homelessness, and brokering and monitoring the appropriate support arrangements to ensure continuity of care.
Outcomes	Data indicate that mothers in this group tend to be poorly educated, have meager work histories, and face multiple medical, mental health, and substance use problems. Their children's lives have lacked stability in terms of housing, education, and periods of separation from their mothers. African-American and Latina women were over-represented in study sites in proportions greater than the national average for homeless populations. (An NIMH-funded study of this project is ongoing; additional outcomes will be available at its conclusion.)
Biggest challenge	The CTI model for families challenges the assumption that homeless mothers with children who are have mental health or substance use disorders require confinement and extended stays in congregate shelter living before they can independently manage their own households. This can be addressed by acquiring buy-in from collaborators and involved agencies, acquiring needed housing resources, evaluating the project with respect to model fidelity, and attaining ongoing involvement of practice innovators to establish thoughtful compromises within local contexts.
How other organizations can adopt	The program is transferable to any community that can align resources needed for housing and conduct relevant training for providers in a CTI model for families. (A manual to guide program replication will be available at the conclusion of the current study.)
Sites	Westchester County, NY
For additional information	See http://www.rfmh.org/csipmh/

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Change Reimbursement Policies to More Fully Support EBPs

Successfully transforming the mental health system, hinges, in part, on better balancing fiscal resources to support using proven, evidence-based practices. The Commission encourages public- and private-sector payers to reframe their reimbursement policies to better support and widely implement EBPs.

The Commission urges the Centers for Medicare and Medicaid Services (CMS) to provide technical assistance to States on how to effectively finance EBPs. This technical assistance should address financing strategies for:

- EBPs in mental health care for adults who are supported with Medicaid funding, including those practices identified through the SAMHSA/Dartmouth project, such as:
  - Family psycho-education,
  - Integrated care of co-occurring mental and substance use disorders,
  - Personal illness management,
  - Supported employment,
  - Assertive community treatment, and
  - Medication management.[165]
- EBPs, such as the Collaborative Care Model, for adults with mental illnesses who are seen in primary health care settings. (*See the description in Goal 4.*)
- EBPs in mental health care for children who are supported with Medicaid funding, such as the clinical aspects of parent-child interaction therapy, multi-systemic therapy, functional family therapy, and treatment foster care.

In addition, the Commission urges CMS to continue to clarify and simplify the waiver process and other administrative processes to facilitate States' using waivers to develop evidence-based practices.

Successfully transforming the mental health system, hinges, in part, on better balancing fiscal resources to support using proven, evidence-based practices.

The Commission notes the particular difficulty of engaging consumers in any type of treatment or support services — including EBPs — after they are released from public institutions, such as hospitals, residential treatment centers, jails, or prisons. For many of these individuals, losing disability benefits when they leave these facilities represents a major barrier to engagement. During extended stays in these institutions, consumers may lose their enrollment, lose their eligibility, or have their eligibility suspended from various disability income programs and from Medicaid or Medicare. When this occurs because rules and regulations have not been properly applied, it reflects confusion or misunderstanding of the rules and regulations. The Commission encourages CMS to collaborate with the Social Security Administration (SSA), the Veterans Administration (VA), and other relevant Federal agencies to clarify existing policy on reinstating disability benefit eligibility — and to explore changing existing policy, as needed. This is critical to facilitate following-up and engaging individuals in treatment and services after they are discharged from public institutions.

The Commission urges SAMHSA to work with CMS to facilitate collaboration between State Mental Health Authorities and Single State Medicaid Agencies.

Address the Workforce Crisis in Mental Health Care

The mental health field must move forward as quickly and efficiently as possible to achieve a more competent and expanded workforce necessary to ensure the full opportunity for recovery, resiliency, and wellness for all Americans with mental illnesses.

Workforce issues are a complex blend of training, professional, organizational, and regulatory issues. Because of this intricacy, the field needs a comprehensive strategic plan to improve workforce recruitment, retention, diversity, and skills training. In fact, without such a plan, it will be difficult to achieve many of the Commission's other recommendations.

To develop this plan, HHS should initiate and coordinate a public-private partnership. The process should broadly include the many non-Federal stakeholders, as modeled by several national groups that are already addressing workforce issues, for example, the Annapolis Coalition on Behavioral Health Workforce Education and the Coalition for Human Resource Development within Systems of Care.

The planning process must address the full lifespan of people with mental illnesses, balancing attention to the specialized needs of children and families, young adolescents, those transitioning to adulthood, adults, and older adults. The plan should draw on the experience gained through previous initiatives to strengthen the workforce, such as the National Institute of Mental Health Staff College, and on efforts to develop model curricula and interdisciplinary training programs. Also, the plan must facilitate its adoption by accrediting and licensing professional organizations.

The plan itself must include strategies to address the severe shortage of practitioners in the mental health workforce. In addition to addressing the workforce crisis within the formal mental health system, the plan must attend to training caregivers in other systems that provide mental health services, including the primary health care system, the corrections system, and schools.

> The mental health field needs a comprehensive strategic plan to improve workforce recruitment, retention, diversity, and skills training.

Every mental health education and training program in the Nation should voluntarily assess the extent to which it:

- Teaches evidence-based approaches to practice;
- Uses teaching methods that have been demonstrated to be effective;
- Offers a curriculum that incorporates the competencies that are essential to practice in contemporary health systems;
- Builds skills in treating people with co-occurring mental and addictive disorders;
- Educates consumers, families, and providers about mental illnesses and about the concepts of recovery and resiliency;
- Engages consumers and families as educators of other health care providers;
- Emphasizes developing cultural competence in clinical practice;
- Ensures that the diversity of the community is reflected among trainees and in the training experience; and
- Prepares students and trainees to work in interdisciplinary environments.

HHS must partner with State agencies that are responsible for the mental health care of children

and adults to develop model, portable curricula to train direct care staff in the Nation's public-sector systems. In the case of service systems for children and families, these curricula must recognize and accommodate a variety of settings and providers, such as social service agencies, schools, and primary care settings.

Some curricula must target individuals who do not have graduate training. Others should be focused on students in graduate training programs or in-service professionals, such as psychologists, psychiatrists, social workers and psychiatric nurses. All training curricula should clearly reflect the perspectives of consumers and families.

In addition, graduate and continuing education programs must train more mental health professionals in effective evidence-based and emerging best practices. The field must move *what we know* into *what we do*. This transformation may require special attention from administrators and policy-makers, as well as from accrediting, licensing, and professional organizations, that have enormous influence on shaping health and mental health workforce education.

The Commission recommends that HHS refine its approach to technology transfer in mental health to ensure that:

- Knowledge is translated more rapidly into the content of training curricula,
- These curricula employ teaching methods of demonstrated effectiveness, and
- Knowledge about effective education, recruitment, and retention strategies inform all public and private efforts to translate science to services.

Graduate and continuing education programs must train more mental health professionals in effective evidence-based and emerging best practices.

RECOMMENDATION **5.4 Develop the knowledge base in four understudied areas: mental health disparities, long-term effects of medications, trauma, and acute care.**

To transform the mental health system, the Commission has identified and highlighted the critical policy areas of:

- Eliminating mental health disparities,
- Assessing the long-term effects of medications,
- Reducing the impact of trauma, and
- Improving acute care.

Research in these understudied areas is essential to ultimately improve the quality of mental health treatments and services.

Study Disparities for Minorities in Mental Health

While many types of disparities exist in mental health care, American Indians, Alaskan Natives, African Americans, Asian Americans, Pacific Islanders, and Hispanic Americans bear a disproportionately high burden because they receive less care and poorer quality of care.[1] Similarly, these groups are significantly under-represented in mental health research and mental health service delivery.[1] (*See Goal 3 for a related discussion.*)

To address this discrepancy, the Commission recommends conducting studies to inform policy decisions and develop a comprehensive research program for minority mental health. In particular, the Commission urges HHS to further study:

- Racial and ethnic minority populations in the areas of psychiatric epidemiology,
- Evidence-based treatment,
- Psychopharmacology,
- Ethnic- and culture-specific therapeutic interventions,
- Diagnosis and assessment,
- Prevention of mental illnesses, and
- Promotion of mental health.

To close the gap that exists in the quality and access of care, the Commission also encourages researchers and grant-makers to focus on the impact of cultural competence on mental health treatment outcomes. Services research should focus on eliminating disparities in access to quality care among racial and ethnic groups.

Study the Effects of Long-term Medication Use

Since many psychotropic medications are treatments and not cures, some individuals with chronic illnesses, including children, must use them on a long-term basis. Current knowledge of their long-term clinical and economic effects is limited and must be expanded. With that goal in mind, the Commission recommends that NIH, undertake a sustained program of research on the long-term positive and negative effects of psychotropic medications for maintenance treatment of mental disorders — including children with serious emotional disturbances.

NIH and the U.S. Food and Drug Administration (FDA) should also provide information to educate consumers on the efficacy, effectiveness, and limitations of psychotropic medications. This research and information should apply to all age groups and special populations, particularly emphasizing the impact of long-term psychotropic medication use for children.

Examine the Effects of Trauma

The Commission recommends that HHS, through NIH, undertake a sustained program of research on the impact of trauma on the mental health of specific populations, such as women, children, and the victims of violent crime, including victims of terrorism. In addition, the Commission recommends that NIH and SAMHSA partner to enhance the evidence base and to evaluate service models for treating post traumatic stress disorder and other trauma-related disorders in public mental health settings.

Address the Problems of Acute Care

While the Commission's focus remains on full community integration for people with mental illnesses across the lifespan, available and effective acute inpatient and other short-term, 24-hour services are essential components of a balanced system of mental health care — especially for those in crisis who need the safety and intensive treatment in such settings.

The Commission recommends that HHS take the lead in:

- Synthesizing the acute care knowledge base,
- Reviewing the many outstanding model programs for acute care that already exist,
- Developing new knowledge as necessary,
- Assessing existing capacities and shortages, and
- Proposing workable solutions to enhance delivering acute care and crisis intervention service.

GOAL 6 Technology Is Used to Access Mental Health Care and Information.

RECOMMENDATIONS

6.1 Use health technology and telehealth to improve access and coordination of mental health care, especially for Americans in remote areas or in underserved populations.

6.2 Develop and implement integrated electronic health record and personal health information systems.

Understanding the Goal

Mental Health Care Lags in Using Technology

Perhaps the most important medical advance of the 21st century will be the application of information technology to health care — allowing all segments of the health system to interact seamlessly and facilitate safe, high-quality care for consumers. An integrated information technology and communications infrastructure is critical to achieving the five preceding goals and transforming mental health care in America.

Although the concept of using technology to improve health care has existed for many decades, the time has come to establish a national health information infrastructure that will encourage the public and private sectors to invest in information technology while adequately safeguarding consumers. To be ultimately useful, systems must be carefully designed to produce care that is safe, effective, patient-centered, timely, efficient, and equitable.[9]

We already know that new technology that aids in administering medications can reduce medical errors and prevent death or unnecessary injuries. However, the technology and communications infrastructure in public and private mental health care lags far behind other sectors.[9]

The time has come to establish a national health information infrastructure that will encourage the public and private sectors to invest in information technology while adequately safeguarding consumers.

To address this technological need in the mental health care system, this goal envisions two critical technological components:

- A robust telehealth system to improve access to care, and
- An integrated health records system and a personal health information system for providers and patients.

Access to Care Is a Concern in Rural and Other Underserved Areas

Emerging technologies provide the means to overcome geographical distances that often hinder access to care. Health technology and telehealth now offer powerful tools to improve access to mental health care in rural, remote, and other underserved areas.

Emerging technologies provide the means to overcome geographical distances that often hinder access to care.

Telehealth — using electronic information and telecommunications technologies to provide long-distance clinical care and consultation, patient and professional health-related education, public health and health administration — is a greatly underused resource for mental health services. Tele-home care and consultations can increase access to mental health care for all patients, but especially for individuals with multiple chronic health conditions, those with severe illness and disability, underserved populations, children, and the frail elderly.

Information Technology Can Now Enhance Medical Records Systems

Information technology is now available to support integrating electronic health record systems. Integrated systems can promote high quality, coordinated services by helping psychiatrists and other physicians, psychologists, social workers, nurses, and other health and human service providers communicate vital health information clearly, confidentially, and when it is needed.

The Institute of Medicine, the National Committee on Vital and Health Statistics, and the National Quality Forum have all proposed widely implementing a paperless, interoperable communications and information technology infrastructure as a way to improve and integrate the Nation's health care system. Mental health can lead this change.

Already, the Federal government is working to establish guidelines and standards to more effectively transmit, communicate, and protect health information. For example, by agreeing to use the same health messaging standards, pharmaceutical codes, imaging standards, and laboratory test names, the country is one giant step closer to speaking a common language and providing better patient care — thus leading the way to a more integrated health care system.

Consumers May Not Have Access to Reliable Health Information

Science has produced large volumes of information about breakthroughs in health promotion, disease prevention, diagnosing and treating illnesses, and recovery. However, a reliable source for this information is not easily or universally available to all Americans.

Although the Commission found that most consumers and families want up-to-date information about the mental disorders, symptoms, treatments, and supportive services for the mental disorders with which they are dealing, such information is seldom available when people need it most. The Commission supports developing a personal health information system to that enables every American to obtain, maintain, and share personal health information.

Achieving the Goal

RECOMMENDATION **6.1 Use health technology and telehealth to improve access and coordination of mental health care, especially for Americans in remote areas or in underserved populations.**

Underserved Populations Can Benefit from Health Technology

Telehealth and e-health technologies hold great promise for improving access to mental health care in many rural, remote, and other underserved areas. By using computers and video cameras, sending e-mail reminders, transmitting results by telephone, and assisting provider follow-up, underserved, rural, and remote communities could significantly improve care for individuals of all ages who have multiple chronic health conditions, including severe illness or disability.

However, a number of barriers must be removed to make these new technologies practical. The Commission recommends that States address the barriers created by restrictive licensure and scope-of-practice restrictions that impede developing technology-based services.

Public and private payers of health care costs do not yet appropriately cover or reimburse for e-health and telehealth services. Reimbursement must become flexible enough to allow evidence-based practices to be implemented, coordinating both traditional clinical care and e-health visits and ensuring that services delivered through new technology are sustained. Doing so will require changing policies and supports in all sectors of the health care industry.

The Commission encourages public and private payers to reimburse for e-health and telemedicine services. The Commission recommends that the U.S. Department of Health and Human Services (HHS) lead a review of how to best deliver and finance these services in consultation with private payers, insurers, State agencies, and other Federal programs.

RECOMMENDATION **6.2 Develop and implement integrated electronic health record and personal health information systems.**

Electronic Medical Records Will Improve Coordination and Quality

With the explosion of scientific advances, new treatments, breakthroughs in promoting health, and medical information, all providers must have high-speed electronic access to the latest evidence-based practice guidelines, best practice models, ongoing clinical trials, scientific research, and other health information.

Studies show that electronic health records improve quality, accountability, and cost-effectiveness of health care services.[179-181] Enhancing communication between informed consumers and health care professionals improves their discussions about treatment options and more knowledgeable decisions. Health care providers, including those in the mental health field, urgently need universal access to real-time, computer-based health records. Successful models of person-centered, integrated, comprehensive electronic health records already exist, such as the Department of Veterans Affairs' (VA) health record system. (*See Figure 6-1.*)

FIGURE 6-1. MODEL PROGRAM: Veterans Administration Health Information and Communication Technology System

Program	U.S. Department of Veterans Affairs (VA), Veterans Health Administration (VHA): Use of Health Information and Communication Technology.
Goal	Improve the quality, access, equity and efficiency of care by using a fully integrated electronic health record system, personal health information systems, and telemedicine.
Features	VHA is the largest integrated health care system in the U.S. with approximately 1,300 sites providing a full continuum of health care services. VA provided mental health services to more than 750,000 veterans in 2002. All VHA medical facilities (clinics, hospitals, and nursing homes) use a fully integrated electronic medical record that is capable of supporting a paperless health record system. The VA system incorporates clinical problem lists, clinic notes, hospital summaries, laboratory, images and reports from diagnostic tests and radiological procedures, pharmacy, computerized order entry, a bar-code medication administration system, clinical practice guidelines, reminders and alerts, and a specialized package of mental health tools. In addition, VA uses innovative information technology and communication systems to give beneficiaries information on benefits and services, allow web-based enrollment, support a national electronic provider credentialing system, provide veterans and their families access to health information and support health care provider education. Telemedicine is used to increase access to primary and specialty care for rural and underserved populations. VA provided approximately 350,000 telemedicine visits and consultations last year. Telemedicine mental health consultations and follow-up visits provide access to these services at locations where they would otherwise be unavailable.
Outcomes	In 2002, the Institute of Medicine reported, "VA's integrated health care information system, including its framework of performance measures, is considered to be one of the best in the nation."[182] Utilizing an electronic health record with a clinical reminder system, VA screens 89% of primary care patients for depression and 81% for substance abuse. In VA, 80% of patients hospitalized for mental illnesses receive follow-up outpatient appointments within 30 days; the next best reported performance by NCQA is 73% and the Medicaid average is only 55%.
Biggest challenge	The public's lack of confidence in the privacy and security of the electronic health record and the lack of national standards for data and communications represent the biggest challenges to implementing such a system.
How other organizations can adopt	High-performance, reliable electronic health record and information systems are currently available for use by any provider, clinic, hospital, or health system. Incentives for adopting electronic health records would speed wider use.
Sites	All VHA clinics, hospitals, and nursing home facilities nationwide

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An integrated, interoperable, electronic health information system — linked by an individual, privacy-protected key card — could enable a virtual health care team and a coordinated system of care to extend across place, providers, plans, and time. Exchanging health information through secure means — including appropriate authorizations from consumers — can connect information from health-related entities with consumers' personal health information. This connection will make important data available at the right times and places to support optimal care and recovery for consumers.

Electronic mental health records may enhance quality by promoting adoption and adherence to evidence-based practices by including:

- Clinical reminders;
- Clinical practice guidelines for prevention, treatment, and monitoring;
- Tools for decision support;
- Direct computer entry of health care instructions and prescription dosages; and
- Patient safety alert systems.

Another promising practice — using individualized, computer-generated reminders — will also become possible with electronic medical records.

Other innovations in mental health care are even more viable with the technology for electronic medical records. For example, using hospital bar-codes to administer medication reduces medication errors and, thus, improves patient safety.[183] Electronic medical records also provide a platform for consumers to receive computerized, clinical instructions and automated alerts for drug interactions, contraindications, and allergies.

The Commission recommends that HHS and VA lead a voluntary public–private initiative to design and adopt a secure, privacy-protected, electronic health record and a system of health information exchange for providers to share information with the approval of consumers. Privacy and security of this system must remain primary concerns. The Commission proposes this national health information infrastructure not as a centralized government database, but rather as a means to connect and exchange health information in the framework of a secure, decentralized network.

- The design initiative should involve Federal, State, and local governments; professional organizations; health care consumers; advocates; providers; payers; purchasers; and other relevant groups.
- The Individualized Plan of Care should be included in the electronic health record and be developed along with the proposed Comprehensive State Mental Health Plan. (*See Goal 2 for a discussion.*)
- The system should include state-of-the-art treatment guidelines and clinical reminders that promote using standardized evidence-based and promising practices in managing serious mental illnesses for adults and serious emotional disturbances for children. System administrators should incorporate these innovations into the electronic medical records systems providers use in clinics, offices, hospitals, and acute care and long-term care settings.

Personal Health Information Systems Can Help Consumers Manage Their Own Care

The Commission found that the general public can now access a great deal of valuable health information through the Internet. Most consumers and families want up-to-date information about the symptoms and mental disorders with which they are dealing, as well as information on effective treatments and supportive services. But today, reliable information is not always available when and how people need it most, and it is not readily or universally accessible to all Americans. Consumers should have the choice and capability to obtain, store, and share their personal health information.

Systems are already available to support access to Internet assessment services and health information sources in order to build a personalized health information library. Consumers can use these systems as research tools to:

- Evaluate the quality of care provided,
- Participate in on-line support groups,
- Evaluate best practices,
- Learn about the most recent treatment breakthroughs, and
- Determine how to best use resources they manage.

Consumers should have the choice and capability to obtain, store, and share their personal health information.

The Network of Care for Mental Health, an individualized mental health resource Web site, provides a model for how consumers can use Internet technology to find pertinent mental health information; identify available services, supports, and community resources; and keep personal records on secure computer servers. (*See Figure 6-2.*)

FIGURE 6-2. MODEL PROGRAM: Individualized Mental Health Resource Web Site

Program	Network of Care for Mental Health
Goal	To help ensure "No Wrong Door" exists for those who need mental health services.
Features	The user-friendly Web site enables consumers and families to find pertinent mental health information; identify available services, supports, and community resources; and keep personal records on secure servers. Consumers and families can search the site's comprehensive *Service Directory* – by age group, diagnosis, program or agency name, key word, or by using the 20-category menu—for mental health treatment and supportive services provided by the county and other organizations. The site also offers up-to-date information about diagnoses, insurance, and advocacy, as well as daily news from around the world concerning mental health.
Biggest challenge	Gathering and organizing an enormous amount of information while making it easily accessible to Network of Care for Mental Health Web site users represents the major challenge.
How other organizations can adopt	The Network of Care Web site can be easily and cost-effectively replicated in any location because the entire infrastructure – and many of the data components; e.g., the library and national links – are identical from one region to another. Only certain county-specific data (e.g., available mental health treatment and support services) must be developed for each new site.
Sites	The San Diego Network of Care for Mental Health Web site was launched April 30, 2003; another is now being developed for Los Angeles County, California.
Web site	http://www.networkofcare.org

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Consumers and families must be assured that their privacy and the confidentiality of their health information are well protected. If health care systems do not make substantial, front-end, ongoing investments to protect privacy, electronic health information systems are doomed to fail. Existing Federal regulations that balance privacy protections and the need for shared information within the health system, such as the Health Insurance Portability and Accountability Act (HIPAA), must be constantly re-examined to ensure that they adequately address both provider and consumer needs.

If health care systems do not make substantial, front-end, ongoing investments to protect privacy, electronic health information systems are doomed to fail.

The Commission recommends that HHS and VA lead a public-private effort to create and promote use of software for Internet access to privacy-protected, personal health information that consumers maintain and control. Consumers and families must be involved in designing, evaluating, and implementing the system that would enable them to personalize their records. The software and training should enable consumers to personalize their health information record through links to key portions of their health records, local consumer support groups, self-care trackers, advance directives, and directories of local service providers located in or near their own ZIP Codes. This personal health information system should include the following elements:

- Electronic copies of key portions of individual health information, including records from health care providers, laboratories, and pharmacies; personal health trackers; and advance directives, care reminders, and self-entered health information;
- Access to Internet assessment services and health information sources so that they can build a personalized health information library;
- Interface with a wide range of services and programs, including prescription, appointment scheduling and reminders, medication refills, participation in consumer and support groups, and alerts to new research findings and projects;
- Availability to the general public, consumers, and families; and
- Universal design to ensure access for people with sensory perceptual and physical disabilities and availability in a broad range of multilingual formats.

Conclusion

This *Final Report* conveys the Commission's bold vision for transforming the existing, often intimidating maze of mental health services into a coordinated, consumer-centered, recovery-oriented mental health system. Although barriers stand in the way, with national resolve and leadership, they will be overcome.

The Commission recognizes that historically Americans have assumed responsibility locally and regionally for working together to meet challenges and to support their neighbors and communities. A major step toward achieving the vision will require genuine collaborative efforts from all parties who deliver or use mental health services and supports. All must recognize the interwoven nature of the diverse programs that make up the mental health system and, in turn, must see where program flexibility and cooperation can be strengthened in the interest of consumers and families.

To transform the mental health care system, the Commission proposes a combination of goals and recommendations that together represent a strong plan for action. No single goal or recommendation alone can achieve the needed changes. No level or branch of government, no element of the private sector can accomplish needed change on its own. To transform mental health care as proposed, collaboration between the private and public sectors and among levels of government is crucial.

Mental illness is the only category of illness for which State and local governments operate distinct treatment systems, making comprehensive care unavailable in the larger health care system. Ultimately, this situation must change, but to do so requires health care reform beyond the Commission's scope.

As has long been the case in America, local innovations under the mantle of national leadership can lead the way for successful transformation throughout the country.

Health care in America is at a pivotal point where reform must occur and mental health must share in that reform. The Nation has a vested interest and a tremendous stake in doing what is right to correct a system with problems that resulted from layering multiple, well-intentioned programs.

The integrated strategy outlined in this *Final Report* can achieve the transformation that will allow adults with serious mental illness and children with serious emotional disturbances to live, work, learn, and participate fully in their communities. Indeed, as has long been the case in America, local innovations under the mantle of national leadership can lead the way for successful transformation throughout the country.

As a Commission, we are grateful to the many strong and courageous individuals who gave their time, and in some cases traveled great distances to share their stories. It is for these individuals — as well as for the ones who continue to go unserved — that we must take swift, courageous action to transform the current maze of services, treatments, and supports into an efficient and cohesive mental health care delivery system. We owe them, their families, and future generations nothing less.

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Title 3 --

The President

Executive Order 13263 of April 29, 2002

President's New Freedom Commission on Mental Health

By the authority vested in me as President by the Constitution and the laws of the United States of America, and to improve America's mental health service delivery system for individuals with serious mental illness and children with serious emotional disturbances, it is hereby ordered as follows:

Section 1. *Establishment.* There is hereby established the President's New Freedom Commission on Mental Health (Commission).

Sec. 2. *Membership.* (a) The Commission's membership shall be composed of:

(i) Not more than fifteen members appointed by the President, including providers, payers, administrators, and consumers of mental health services and family members of consumers; and

(ii) Not more than seven ex officio members, four of whom shall be designated by the Secretary of Health and Human Services, and the remaining three of whom shall be designated--one each--by the Secretaries of the Departments of Labor, Education, and Veterans Affairs.

(b) The President shall designate a Chair from among the fifteen members of the Commission appointed by the President.

Sec. 3. *Mission.* The mission of the Commission shall be to conduct a comprehensive study of the United States mental health service delivery system, including public and private sector providers, and to advise the President on methods of improving the system. The Commission's goal shall be to recommend improvements to enable adults with serious mental illness and children with serious emotional disturbances to live, work, learn, and participate fully in their communities. In carrying out its mission, the Commission shall, at a minimum:

(a) Review the current quality and effectiveness of public and private providers and Federal, State, and local government involvement in the delivery of services to individuals with serious mental illnesses and children with serious emotional disturbances, and identify unmet needs and barriers to services.

(b) Identify innovative mental health treatments, services, and technologies that are demonstrably effective and can be widely replicated in different settings.

(c) Formulate policy options that could be implemented by public and private providers, and Federal, State, and local governments to integrate the use of effective treatments and services, improve coordination among service providers, and improve community integration for adults with serious mental illnesses and children with serious emotional disturbances.

Sec. 4. *Principles*. In conducting its mission, the Commission shall adhere to the following principles:

(a) The Commission shall focus on the desired outcomes of mental health care, which are to attain each individual's maximum level of employment, self-care, interpersonal relationships, and community participation;

(b) The Commission shall focus on community-level models of care that efficiently coordinate the multiple health and human service providers and public and private payers involved in mental health treatment and delivery of services;

(c) The Commission shall focus on those policies that maximize the utility of existing resources by increasing cost effectiveness and reducing unnecessary and burdensome regulatory barriers;

(d) The Commission shall consider how mental health research findings can be used most effectively to influence the delivery of services; and

(e) The Commission shall follow the principles of Federalism, and ensure that its recommendations promote innovation, flexibility, and accountability at all levels of government and respect the constitutional role of the States and Indian tribes.

Sec. 5. *Administration*. (a) The Department of Health and Human Services, to the extent permitted by law, shall provide funding and administrative support for the Commission.

(b) To the extent funds are available and as authorized by law for persons serving intermittently in Government service (5 U.S.C. 5701-5707), members of the Commission appointed from among private citizens of the United States may be allowed travel expenses while engaged in the work of the Commission, including per diem in lieu of subsistence. All members of the Commission who are officers or employees of the United States shall serve without compensation in addition to that received for their services as officers or employees of the United States.

(c) The Commission shall have a staff headed by an Executive Director, who shall be selected by the President. To the extent permitted by law, office space, analytical support, and additional staff support for the Commission shall be provided by executive branch departments and agencies.

(d) Insofar as the Federal Advisory Committee Act, as amended, may apply to the Commission, any functions of the President under that Act, except for those in section 6 of that Act, shall be performed by the Department of Health and Human Services, in accordance with the guidelines that have been issued by the Administrator of General Services.

Sec. 6. *Reports.* The Commission shall submit reports to the President as follows:

(a) Interim Report. Within 6 months from the date of this order, an interim report shall describe the extent of unmet needs and barriers to care within the mental health system and provide examples of community-based care models with success in coordination of services and providing desired outcomes.

(b) Final Report. The final report will set forth the Commission's recommendations, in accordance with its mission as stated in section 3 of this order. The submission date shall be determined by the Chair in consultation with the President.

Sec. 7. *Termination.* The Commission shall terminate 1 year from the date of this order, unless extended by the President prior to that date.

George W. Bush
The White House,
April 29, 2002.

Acknowledgments

The Commission deeply appreciates the more than 2,300 persons who shared comments, personal stories, and recommendations through its web site, at public hearings, and in letters and e-mails. Their insightful and heartfelt comments have strengthened and helped shape the work of the President's New Freedom Commission on Mental Health.

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Acronyms

ACF	Administration for Children and Families
AD/HD	Attention Deficit Hyperactivity Disorder
ADA	Americans with Disabilities Act
BBA	Balanced Budget Act
CMHS	Center for Mental Health Services
CSAT	Center for Substance Abuse Treatment
CMS	Center for Medicare and Medicaid Services
DOJ	U.S. Department of Justice
EBPs	Evidence-based Practices
ED	U. S. Department of Education
FCTI	Family Critical Time Intervention Model
FDA	U.S. Food and Drug Administration
GAO	General Accounting Office
HCBS	Home and Community-based Services
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HRSA	Health Resources and Services Administration
HUD	U.S. Department of Housing and Urban Development
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IMDs	Institutions for Mental Diseases
IOM	Institute of Medicine
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NSSP	National Strategy for Suicide Prevention
OCR	Office for Civil Rights
PTSD	Post-traumatic Stress Disorder
SAMHSA	Substance Abuse and Mental Health Services Administration
SSA	Social Security Administration
SSDI	Social Security and Disability Income
SSI	Social Security Income
TANF	Temporary Assistance for Needy Families
TMAP	Texas Medication Algorithm Project
TWWIIA	The Ticket to Work and Work Incentives Improvement Act
VA	Department of Veterans Affairs
VHA	Veterans Health Administration
WHO	World Health Organization

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